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A Qualitative Examination of Military and Nonmilitary Personnel

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14. ABSTRACT This project was designed to find out how successful adjustment happens after SCI. We used a mail survey to identify individuals with SCI who reported doing well, then recruited a stratified sample of 60 respondents identified as flourishing to participate in in-depth qualitative assessments. 472 eligible surveys were completed in Phase 1 of the project. Findings from the qualitative phase suggest that flourishing after SCI does not appear to be one thing or one approach; rather it seems that individuals may need two or more of the following strengths or resources: positive attitude and motivation; a history of confidence and success; skills of communication, problem-solving and adapting; resources and access to the right services at the right time; and the support of family and friends. Finally, our interviews seemed to make clear that happiness and a sense of meaning in life were different, though often connected constructs. Knowledge translation activities have, and continue to be, conducted and include peer-review publications, presentations, and workshops.				
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Introduction

This project was designed to find out how successful adjustment happens after SCI. We started by identifying “successful” and resilient individuals with SCI via a mail survey to the known population of individuals with SCI served by the associated project sites (Phase 1). We then recruited a stratified sample of successful individuals and used qualitative techniques to gather details from them about their lives and experiences (Phase 2). We focused on finding out about the thoughts they had, the decisions they made, and the behaviors they performed in the first few years after injury, as well as what factors influenced these. By illuminating the process of positive adjustment and successful self-regulation after SCI and articulating specific and concrete cognitions, decisions, and behaviors, this project sought to provide foundational information to enhance existing intervention and develop new assessments and programs.

Body

We have completed the implementation of research activities identified in the scope of work for this grant project. As previously reported, the project initially encountered significant delays in obtaining all of the necessary approvals from the various Human Subjects Review Boards and the Department of Defense. After those important requirements were completed, though, we worked diligently to complete all parts of Phase 1 and Phase 2 and to maintain contact with the various project and contract officers. We are very excited with the level of engagement of participants, their responses to this project, and the amount and quality of data we have collected. We are using these findings to conduct dissemination and knowledge translation activities and expect to do so for several years. Specific outputs have included presentations and workshops at national and international events, the development and submission of manuscripts.

Regulatory Review and Approval Process

This project involved two phases (mail survey and qualitative interviews) which were submitted as two separate studies to the University of Michigan IRB. In addition, the mail survey (Phase 1) study was submitted to the IRB at the Rehabilitation Institute of Michigan and the Ann Arbor VA. While the DoD considers the Paralyzed Veterans of Michigan (PVA) as its own site, it does not have an IRB and so is included under the University of Michigan IRB. As approvals were received from sites, the approvals were submitted to the DOD. The second phase was the qualitative interviews. This was approved to be conducted at the University of Michigan. All sites are approved or closed (RIM) as appropriate.

Phase 1: Screening Survey

The survey process was completed for all sites of the study by 30 JUN 2015. We mailed surveys to 1912 individuals with spinal cord injury. From these, we had at least 152 returned because of bad addresses or ineligibility and received completed surveys from 641 individuals. We later determined that there were surveys received from individuals who were not eligible. In particular, one of our partner organizations sent the mail survey to their entire membership list rather than just individuals with traumatic spinal cord injury. In addition, we found that some of the individuals recruited from the University of Michigan had a mention of a SCI in their medical records but were later determined not to have a traumatic SCI. To remove these individuals, we reviewed the medical records of all participants from the University of Michigan. This procedure revealed that 159 of the original survey respondents and 55 of the 169 individuals who were thought to be eligible for Phase 2 of this study had to be excluded because of misinformation about their eligibility. So of the 641 survey that were received, we wound up with 472 valid and eligible responses, giving us a 26.8% response rate for our mailing.

The survey contained questions about demographic and injury-related information, the Satisfaction with Life Scale (Post et al., 2012), the Flourishing Scale (Diener et al., 2010), questions about level of happiness and social comparisons, and an open-ended question where the respondent could share their story about how they were able to be resilient after their injury.

Respondents to our survey (see Table 1) were predominately white, male, and college-educated. They tended to live in rural areas. The sample reflected respondents from a wide range of income levels (from under \$20,000 to over \$80,000 household income per year).

Table 1. Survey Sample Characteristics

Characteristic	n (%) or Mean ± SD (range)
Age	53.7 ± 15.2 (19-93)
Gender	
Male	375 (79.4%)
Female	89 (18.9%)
Missing	8 (1.7%)
Race	
White	385 (81.6%)
African American	40 (8.5%)
Multiracial	19 (4%)
Other	18 (3.8%)
Missing	10 (2.1%)
Education	
Some high school or less	26 (5.5%)
High school diploma / GED	108 (22.9%)
Some college / Associate's degree	184 (39%)
Bachelor's degree or higher	146 (30.9%)
Missing	8 (1.7%)
Marital Status	
Single	125 (26.5%)
Married / Partnered	230 (48.7%)
Separated / Divorced	90 (9.1%)
Widowed	19 (4%)
Missing	8 (1.7%)
Income	
<\$29,999	156 (33.1%)
\$30K-\$59,999	118 (25%)
\$60K+	140 (29.7%)
Missing	58(12.3%)
Residence	
Urban	61 (12.9%)
Suburban	168 (35.6%)
Small town / rural	223 (47.2%)
Missing	20 (4.2%)

Respondents were also 47.6% military Veterans, with about 17% coming from non-Veteran-centric sources (U-M and RIM; see Table 2). This is notable because of the U.S. Census estimate that only about 6% of the population are Veterans (United States Census Bureau, n.d.) and only .09% of the total U.S. population have a spinal cord injury (NSCISC, 2016).

Table 2. Characteristics of Military Sample (n = 225 / 47.6% of survey respondents)

Characteristic	Yes		No		Missing	
	n	%	n	%	n	%
Participated in combat	69	30.70%	150	66.70%	6	2.70%
Receives VA benefits	157	69.80%	64	28.40%	4	1.80%
Receive care at VA health facility	168	74.70%	55	24.40%	2	0.90%
Service-connected SCI	86	38.20%	134	59.60%	5	2.20%

Respondents tended to have incomplete cervical injuries (see Table 3); the SCI population is estimated to be 66.3% incomplete (NSCIC, 2016), compared to our sample being 62.7% incomplete. They were on average 18 years post-injury.

Table 3. Injury Characteristics

Characteristic	n (%) or Mean ± SD (range)
Level of Injury	
C1 - C4	81 (17.2%)
9 (11.1%) require a ventilator	
C5 - C8	124 (26.3%)
T1 - T12	153 (32.4%)
L1 - S3	42 (8.9%)
Unsure	49 (10.4%)
Missing	23 (4.9%)
Years Since Injury	18 ± 14.6 (0.3-75)
Feeling below level of injury	296 (62.7%)
Movement below level of injury	272 (57.6%)

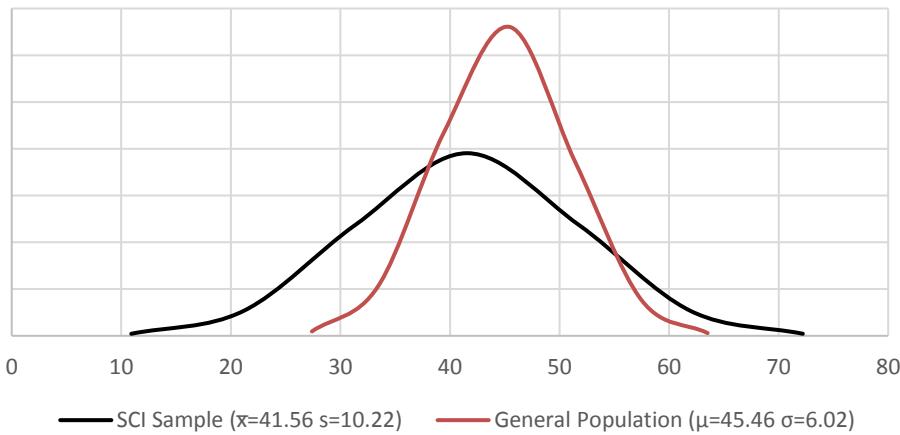
This is the first study that we know of that has used the Flourishing Scale with individuals with SCI. As responses to the Satisfaction with Life Scale (SWLS) were also collected (see Table 4), these data will be useful in supporting a more positive focus on life after SCI. A factor analysis of the Flourishing Scale for individuals with SCI is the focus of one of the manuscripts (Perera et al.) that has been submitted to *Rehabilitation Psychology*.

Table 4. Satisfaction with Life Scale (SWLS) Comparisons

Sample	n	Mean ± SD
Normative sample	129	21.0 ± 7.7
Survey sample	456	18.86 ± 8.10
Interviewed sample	59	23.17 ± 7.75

Descriptive analyses of Phase 1 participants' responses demonstrate a broader range of scores as well as a somewhat lower average on the Flourishing Scale (see Figure 1).

Figure 1. Comparison of Distributions of Flourishing Scale Scores



As shown in Table 5, scores were negatively correlated with current age ($r = -.156$ $p=0.001$) and number of secondary conditions ($r = -.321$ $p=0.000$) and positively correlated with household income ($r = .212$ $p=0.000$), and education ($r = .203$ $p=0.000$). Time since injury, gender, and level of SCI do not appear related to outcomes on the Flourishing Scale (see Table 6).

Table 5. Flourishing Scale Total Score Correlations

	Pearson correlation	Significance (two-tailed)	N
Secondary conditions	-.321*	0.000	452
Age	-.156*	0.001	449
Household income	.220*	0.000	398
Level of education	.203*	0.000	444

* Correlation is significant at the 0.01 level (two-tailed).

Table 6. Notable Insignificant Correlations to Flourishing Scale Total Score

	Pearson correlation	Significance (two-tailed)	N
Years since injury	0.032	0.502	441
Level of SCI	-0.075	0.121	433
Gender	0.068	0.152	444

Examination of Flourishing Scale scores between groups reveals that Veterans (see Table 7), survey respondents who were unemployed (see Table 8), and those who see themselves as worse off when compared to others (see Table 9) have lower scores. Time since injury, gender, and level of SCI do not appear related to outcomes on the Flourishing Scale (see Table X).

Table 7. Flourishing Scale Total Score and Veteran Status

Military Veteran	N	Mean \pm SD (range)
Yes	212	40.10 \pm 11.00 (8-56)
No	234	43.10 \pm 9.18 (8-56)

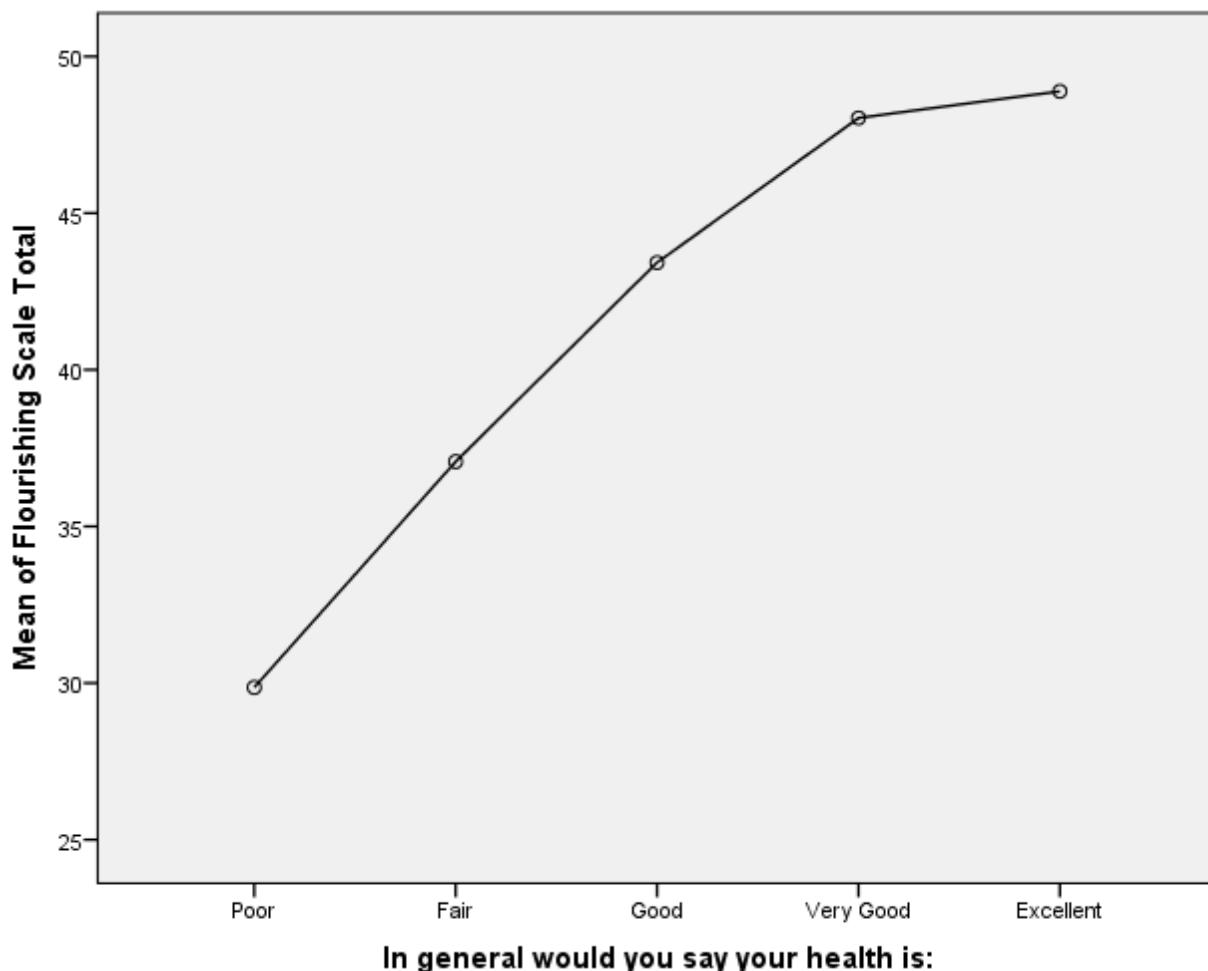
Table 8. Flourishing Scale Total Score and Employment Status

Employed in a Paying Job	N	Mean ± SD (range)
Yes	106	46.59 ± 8.99 (8-56)
No	336	39.84 ± 10.14 (8-56)

Table 9. Flourishing Scale Total Score by Self-Comparisons Rating

Comparison	N	Mean ± SD (range)
Better off	91	47.46 ± 9.58
Worse off	156	35.34 ± 9.79
About the same	192	43.96 ± 7.64
Total	439	41.62 ± 10.09

Figure 2 displays the definitive differences in Flourishing Scale score compared to personal health comparison.

Figure 2. Flourishing Scale Total compared to Health Comparison

A multiple linear regression was calculated to predict the Flourishing Scale Score based on four models: 1) age, race, gender, military service; 2) level of injury and time since injury; 3) employment, income, level of education, health

comparison, and number of secondary conditions; and 4) their self-reported comparison to others (better off, worse off, about the same).

The strongest effects for models 2-4 were age ($\beta = -0.186$), health rating ($\beta = 0.401$), and health rating ($\beta = 0.405$), respectively. There was no statistically significant ($p \leq .05$) individual predictor in Model 1.

For example, in Model 2, as their age increases, the Flourishing Scale score would decrease by .186 standard deviations (1.9 "points"). The possible Flourishing Scale scores range from 8-56. A drop of 1.9 per year suggests there is at least a considerable drop in one's view of himself/herself over time. In a simple regression analysis with only age as an independent variable, the β is -.156 ($p= 0.001$).

Table 10. Flourishing Scale Linear Regression Model Summary^e

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.266 ^a	0.071	0.041	9.655
2	.347 ^b	0.121	0.087	9.420
3	.591 ^c	0.349	0.314	8.167
4	.592 ^d	0.351	0.313	8.169

a. Predictors: Flourishing Scale Total (Constant), Other (race), Middle-Eastern, Asian, Native Hawaiian Other Pacific Islander, American Indian, Alaska Native, Black / African-American, 1. How old are you? , Hispanic / Latino, Gender, Have you ever served in the military?, White

b. Predictors: Flourishing Scale Total (Constant), Other (race), Middle-Eastern, Asian, Native Hawaiian Other Pacific Islander, American Indian, Alaska Native, Black / African-American, 1. How old are you? , Hispanic / Latino, Gender, Have you ever served in the military?, White, Level of Injury , Years since injury

c. Predictors: Flourishing Scale Total (Constant), Other (race), Middle-Eastern, Asian, Native Hawaiian Other Pacific Islander, American Indian, Alaska Native, Black / African-American, 1. How old are you? , Hispanic / Latino, Gender, Have you ever served in the military?, White, Level of Injury , Years since injury , Number of Secondary Conditions, Level of Education , Household Income, Employed for Pay , Health Rating

d. Predictors: Flourishing Scale Total (Constant), Other (race), Middle-Eastern, Asian, Native Hawaiian Other Pacific Islander, American Indian, Alaska Native, Black / African-American, 1. How old are you? , Hispanic / Latino, Gender, Have you ever served in the military?, White, Level of Injury , Years since injury , Number of Secondary Conditions, Level of Education , Household Income, Employed for Pay , Health Rating, Comparison to Other (race)s (better off, worse off, about the same)

e. Dependent Variable: Flourishing Scale Total

Table 11. Flourishing Scale Linear Regression ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	2424.449	11	220.404	2.364	.008 ^b
	Residual	31788.673	341	93.222		
	Total	34213.122	352			
2	Regression	4129.255	13	317.635	3.579	.000 ^c
	Residual	30083.866	339	88.743		
	Total	34213.122	352			
3	Regression	11933.837	18	662.991	9.939	.000 ^d

	Residual	22279.285	334	66.704		
	Total	34213.122	352			
4	Regression	11993.190	19	631.221	9.460	.000e
	Residual	22219.932	333	66.727		
	Total	34213.122	352			

a. Dependent Variable: Flourishing Scale Total

b. Predictors: Flourishing Scale Total (Constant), Other (race), Middle-Eastern, Asian, Native Hawaiian Other Pacific Islander, American Indian, Alaska Native, Black / African-American, 1. How old are you? , Hispanic / Latino, Gender, Have you ever served in the military?, White

c. Predictors: Flourishing Scale Total (Constant), Other (race), Middle-Eastern, Asian, Native Hawaiian Other Pacific Islander, American Indian, Alaska Native, Black / African-American, 1. How old are you? , Hispanic / Latino, Gender, Have you ever served in the military?, White, Level of Injury , Years since injury

d. Predictors: Flourishing Scale Total (Constant), Other (race), Middle-Eastern, Asian, Native Hawaiian Other Pacific Islander, American Indian, Alaska Native, Black / African-American, 1. How old are you? , Hispanic / Latino, Gender, Have you ever served in the military?, White, Level of Injury , Years since injury , Number of Secondary Conditions, Level of Education , Household Income, Employed for Pay , Health Rating

e. Predictors: Flourishing Scale Total (Constant), Other (race), Middle-Eastern, Asian, Native Hawaiian Other Pacific Islander, American Indian, Alaska Native, Black / African-American, 1. How old are you? , Hispanic / Latino, Gender, Have you ever served in the military?, White, Level of Injury , Years since injury , Number of Secondary Conditions, Level of Education , Household Income, Employed for Pay , Health Rating, Comparison to Other (race)s (better off, worse off, about the same

Table 12. Flourishing Scale Linear Regression Coefficients

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error			
1	Flourishing Scale Total (Constant)	40.699	4.475		9.094	0.000
	Age	-0.072	0.037	-0.113	-1.961	0.051
	Gender	-0.146	1.371	-0.006	-0.106	0.915
	Military Service	1.825	1.209	0.092	1.510	0.132
	White	2.831	3.134	0.094	0.903	0.367
	Black / African-American	3.836	3.572	0.104	1.074	0.284
	Asian	14.286	10.226	0.077	1.397	0.163
	Middle-Eastern	14.186	10.201	0.077	1.391	0.165
	Native Hawaiian Other Pacific Islander	8.007	7.037	0.061	1.138	0.256
	American Indian, Alaska Native	-6.569	3.151	-0.111	-2.085	0.038
	Hispanic / Latino	-5.307	3.911	-0.080	-1.357	0.176
	Other (race)	-1.906	3.336	-0.034	-0.571	0.568
2	Flourishing Scale Total (Constant)	40.448	4.538		8.914	0.000
	Age	-0.119	0.038	-0.186	-3.148	0.002
	Gender	0.193	1.341	0.008	0.144	0.886
	Military Service	2.602	1.203	0.131	2.162	0.031
	White	2.557	3.059	0.085	0.836	0.404
	Black / African-American	3.825	3.485	0.103	1.098	0.273
	Asian	15.469	9.981	0.084	1.550	0.122
	Middle-Eastern	12.572	9.962	0.068	1.262	0.208

Native Hawaiian Other Pacific Islander	8.637	6.922	0.066	1.248	0.213
American Indian, Alaska Native	-5.830	3.081	-0.098	-1.893	0.059
Hispanic / Latino	-6.026	3.819	-0.091	-1.578	0.116
Other (race)	-2.799	3.262	-0.049	-0.858	0.391
Years since injury	0.175	0.041	0.249	4.300	0.000
Level of Injury	-0.639	0.443	-0.076	-1.443	0.150
3 Flourishing Scale Total (Constant)	28.477	5.330		5.343	0.000
Age	-0.019	0.035	-0.029	-0.541	0.589
Gender	-0.132	1.169	-0.005	-0.113	0.910
Military Service	1.568	1.051	0.079	1.491	0.137
White	5.215	2.677	0.173	1.948	0.052
Black / African-American	9.246	3.090	0.250	2.992	0.003
Asian	22.452	8.767	0.121	2.561	0.011
Middle-Eastern	9.621	8.712	0.052	1.104	0.270
Native Hawaiian Other Pacific Islander	7.116	6.026	0.054	1.181	0.239
American Indian, Alaska Native	-4.999	2.701	-0.084	-1.851	0.065
Hispanic / Latino	-4.955	3.352	-0.075	-1.478	0.140
Other (race)	1.162	2.888	0.021	0.402	0.688
Years since injury	0.125	0.036	0.177	3.476	0.001
Level of Injury	-0.336	0.388	-0.040	-0.867	0.387
Employed for Pay	-3.198	1.142	-0.145	-2.800	0.005
Household Income	0.536	0.268	0.102	1.998	0.047
Health Rating	4.143	0.591	0.401	7.007	0.000
Level of Education	-0.400	0.481	-0.044	-0.831	0.407
Number of Secondary Conditions	-0.240	0.285	-0.044	-0.842	0.400
4 Flourishing Scale Total (Constant)	26.774	5.628		4.757	0.000
Age	-0.016	0.035	-0.026	-0.472	0.638
Gender	-0.166	1.169	-0.007	-0.142	0.887
Military Service	1.556	1.051	0.079	1.480	0.140
White	5.298	2.678	0.176	1.978	0.049
Black / African-American	9.324	3.092	0.252	3.016	0.003
Asian	23.144	8.799	0.125	2.630	0.009
Middle-Eastern	9.192	8.726	0.050	1.053	0.293
Native Hawaiian Other Pacific Islander	7.279	6.030	0.055	1.207	0.228
American Indian, Alaska Native	-4.891	2.704	-0.082	-1.809	0.071
Hispanic / Latino	-4.562	3.378	-0.069	-1.350	0.178
Other (race)	0.939	2.898	0.017	0.324	0.746
Years since injury	0.124	0.036	0.176	3.443	0.001
Level of Injury	-0.319	0.388	-0.038	-0.823	0.411
Employed for Pay	-3.215	1.142	-0.145	-2.814	0.005
Household Income	0.528	0.269	0.101	1.968	0.050
Health Rating	4.188	0.593	0.405	7.059	0.000
Level of Education	-0.342	0.485	-0.038	-0.705	0.481
Number of Secondary Conditions	-0.237	0.285	-0.044	-0.832	0.406

Comparison to Other (race)s (better off, worse off, about the same)	0.545	0.577	0.043	0.943	0.346
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The issue of resilience and ability to “bounce back from a challenge” appeared to resonate with individuals with SCI living in the community such that approximately half of survey participants took the time to respond to an open-ended question about this. Qualitative analysis revealed eight categories of responses that provided insight into self-reported facilitators and barriers associated with adjustment and happiness following SCI. These eight categories are: resilience, general outlook on life, social support and social relationships, religion or faith in a higher power, physical health and functioning, mood, comparisons, and resources. These categories encompassed 18 overlapping themes that increased understanding of the factors that are related to resilience among adults with SCI living in the community. Consistent with previous research, the majority of respondents described themselves as being happy all or most of the time. Overall, the categories and themes articulated appear to be consistent with the research supporting the use of the Stress Appraisal and Coping Model to understand adjustment following SCI. Our findings highlight the frequency that individuals with SCI perceive themselves as being happy and how this appears to be connected with self-identification as being resilient, employing strategies to reframe one’s experience, and having a sense of support from friends or a higher power. A primary limitation of this analysis, though, is self-selection bias; that is, only individuals who decided to complete the open-ended question and participate in the larger survey were included. Although the sample remains fairly large and diverse for a qualitative study, it is undoubtedly weighted to reflect the perspectives of individuals with SCI who had the energy and motivation to participate. A paper detailing this analysis was published in *Topics in Spinal Cord Injury Rehabilitation* that was released in the Spring of 2016 (Duggan et al.).

Phase 2: Qualitative Component of Project – Individual Interviews and Assessments

Phase 2 of the study consisted of the qualitative portion of the project, including a semi-structured interview and administration of supplemental assessments of personality, perceived social support, and cognitive flexibility. Interviews were conducted in person either at the participant’s home or another location that they identified as safe, comfortable, and convenient for them. The semi-structured interview consisted of eight questions designed by the project investigators to explore the cognitions, decisions, and behaviors associated with successful adjustment to SCI (see Appendix A). These were supplemented by brief measures of cognitive flexibility (the Stroop Neurophysiological Screening Tests, SNST; Trenerry et al., 1989), personality (NEO Five-Factor Inventory-3, NEO-FFI-3; McCrae et al., 2005) and social support (Interpersonal Support Evaluation List-12, ISEL-12; Cohen et al., 1985).

Potential participants for this phase of the project consisted of a stratified sample of respondents who participated in Phase 1 of the project. We used the Flourishing Scale to operationalize the definition of “success after adjustment to SCI” and determine eligibility for the interviews. Initially, the cutoff for eligibility was set at 48 or higher, which reflected individuals scoring in the top third of respondents; however, as we proceeded we realized that we would not be able to fill all of recruit and interview sufficient participants in low-frequency categories if we continued to use this cutoff. As a result (and as previously identified as a potential strategy if just this problem arose), we adjusted eligibility to a Flourishing Scale of 41.56, which reflected the mean of survey respondents; however, one individual (with a Flourishing Scale score of 40) was mistakenly included as part of the Phase 2 sample and so his data remain in the qualitative analyses.

We attempted to recruit at least five individuals from each stratification group, for a total of 60 participants. We used three factors to stratify individuals. These factors were military Veteran status, resource level, and years since injury. We split up resources by using the survey responses for household income, auto insurance, and service connection for SCI. In Michigan, if the trauma that results in SCI is related to an automobile, these individuals have increased assistance from their auto insurance company (see Table 13). Years since injury was split into two groups: 2 to 10 years and more than 10 years since injury.

Table 13. Resource Level Determination

Household Income	Auto Insurance or Service Connection	Resource Level
<\$29,999	No	low
	Yes	medium

\$30K-\$59,999	No	medium
	Yes	high
\$60K+	No	high
	Yes	high

This has resulted in the following breakdown of participants in each stratification category (Table 14):

Table 14. Interview Stratification

Group	Resource Level	2-10		10+	
		Eligible	Completed	Eligible	Completed
Military (n=29)		13	5	39	24
	Low	7	1	11	7
	Medium	4	2	9	5
	High	2	2	19	12
Non-military (n=31)		25	16	35	15
	Low	9	6	9	4
	Medium	7	5	13	5
	High	9	5	13	6

All 60 interviews were completed between November 2014 and January 2016. Figure 3 shows a map of the locations of each interviewee. Table 15 includes the breakdown of the characteristics of those interviewed.

Figure 3: Map of Phase 2 Participants

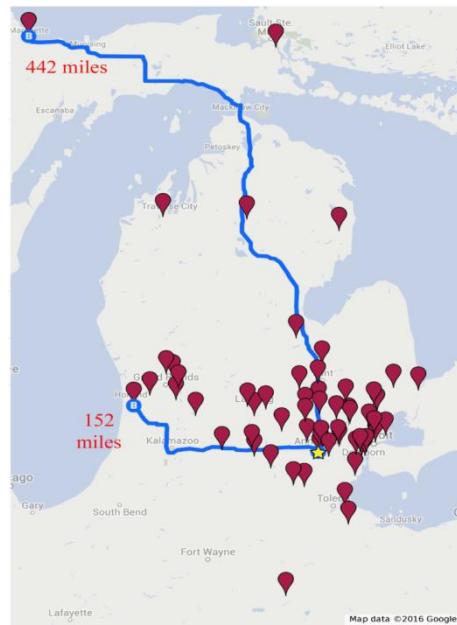


Table 15. Interviewed Sample Characteristics

Characteristic	n (%) or Mean ± SD (range)
Age	50.6 ± 15.8 (19-93)
Gender	
Male	51 (85%)

Female	9 (15.0%)
Race	
White	51 (85%)
Black	4 (6.7%)
Native Hawaiian or Other Pacific Islander	1 (1.7%)
Multiracial	4 (6.7%)
Education	
High school / GED	13 (21.7%)
Some college / Associates degree	24 (40%)
Bachelor's degree or higher	23 (38.3%)
Marital Status	
Single	18 (30%)
Married / Partnered	27 (45%)
Divorced	12 (20%)
Widowed	2 (3.3%)
Missing	1 (1.7%)
Household Income	
<\$29,999	156 (33.1%)
\$30K-\$59,999	118 (25%)
\$60K+	140 (29.7%)
Missing	58 (12.3%)
Residence	
Urban	8 (13.3%)
Suburban	22 (36.7%)
Small town / rural	28 (46.7%)
Missing	2 (3.3%)

Table 16. Characteristics of Interviewed Military Sample (n=29 / 48.3%)

Characteristic	n (%)		
	Yes	No	Missing
Participated in combat	10 (34.48%)	18 (62.07%)	1 (3.45%)
Receive VA benefits	19 (65.52%)	10 (34.48%)	
Receive care at VA health facility	22 (75.86%)	7 (24.14%)	
Service-connected for SCI	9 (31.03%)	20 (69.97%)	

Table 17. Interviewed Sample Injury Characteristics

Characteristic	n (%) or Mean ± SD (range)
Level of Injury	
C1 - C4	10 (16.7%)
1 (10%) requires a ventilator	
C5 - C8	16 (26.7%)
T1 - T12	25 (41.7%)
L1 - S3	7 (11.7%)
Unsure	2 (3.3%)
Years Since Injury	16.5 ± 12.2 (1-47)

Feeling Below Level of Injury	37 (61.7%)
Movement Below Level of Injury	31 (51.7%)

The ISEL-12 is a measure of interpersonal support. It has statements such as “If a family crisis arose, it would be difficult to find someone who could give me good advice about how to handle it.” Respondents are asked to indicate how true each statement is for them (definitely false, probably false, probably true, definitely true). Higher scores reflect higher levels of perceived social support. The purpose for including this measure was to determine how much an individual felt that they could reach out to others for assistance. As shown in Figure 4, mean scores for Phase 2 participants were slightly higher than the norms for the general population, suggesting that adults who have successfully adjusted to their SCI feel as if they have a support network that can provide emotional and practical support. Table 18 shows the Z-test results. The p value of .01 suggests that the sample has a significantly higher mean than the normative sample.

Figure 4. ISEL-12 Total Score Comparison

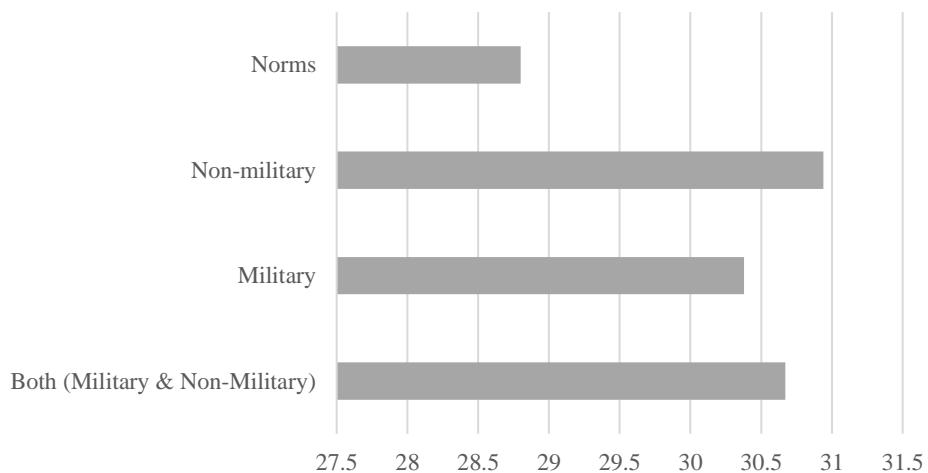
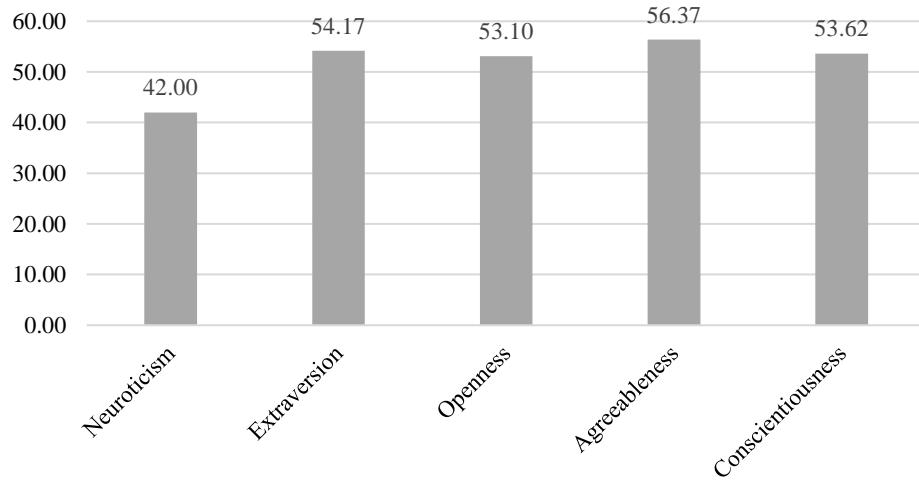


Table 18. One Sample Z-Test of ISEL-12

z statistic	p value
2.54	0.01

The NEO-FFI-3 is a measure of personality characteristics whose five scales reflect Conscientiousness, Agreeableness, Openness, Extraversion, and Neuroticism. Respondents indicate their degree of agreement with 60 statements (such as “I am not a worrier”), from strongly disagree to strongly agree. Higher scores on each scale reflect more of the identified personality characteristic. Figure 5 shows the interviewed sample’s means. Of note, adults with SCI who were identified as successfully adjusting to SCI showed lower than average T-scores on the Neuroticism scale, suggesting that this sample may display more emotional stability and fewer disruptive emotions which may allow them to adapt better. All other T-scores were similar to the normative sample.

Figure 5. NEO-FFI-3 T-Scores



The Stroop test is a test of cognitive flexibility. The respondent is first asked to read aloud a list of color words (red, blue, green, etc.) as fast as they can. They have two minutes to complete the task. This is the Color Task. The maximum score is 112 and 83.3% of those interviewed scored the maximum. Only six of the Phase 2 participants who were able to complete this assessment did not score the maximum; this is what accounts for the rather large discrepancy between the standard deviations of the normative sample and this sample (see Table 19). The second part of the Stroop test is the Color-Word test. This one changes the task by having the respondent read aloud the color of the ink, not the word itself. For example, there may be the word blue but it is printed in red ink. The correct response for that is “red.” They had two minutes to complete this task as well. The Color-Word task results are similar to the normative sample, but slightly lower. Some individuals did not complete this assessment due to a variety of reasons with the most common being a vision problem. The Stroop test was performed at the same location as the interview. That is, not in a controlled environment and with varying levels of light. This test also requires rapid audible responses, which was not possible with one of the respondents who was on a ventilator and was only able to whisper.

Table 19. STROOP scores SCI Sample vs. Normative Sample

Task & Sample	18-49 years (SD)	50+years (SD)
Color Task		
Normative	111.94 (0.23)	111.92 (0.27)
SCI	111.83 (0.51)	111.58 (1.43)
Color-Word Task		
Normative	104.9 (10.22)	93.98 (18.41)
SCI	102.31 (10.84)	92.06 (17.90)

The findings and limited variability on this measure of cognitive flexibility suggest that a baseline level of attention and cognitive flexibility may be required by those with SCI who are able to adapt successfully. These findings highlight the need for more research to determine what cognitive characteristics may translate to functionally more significant gains after SCI.

Military vs Non-military Quantitative Comparisons in the Interview Sample

There were some significant differences in demographic characteristics. The military group was older (11.15 p=0.005), had more years since their injury (7.98 p=0.010). They also tended to rate their health slightly lower (-0.68 p=0.006).

We compared the quantitative measures from Phase 1 and Phase 2 of those we interviewed. The findings suggest that there was no statistical difference in the results save for one subscale of the NEO-FFI-3 (-7.13, sd= -3.27, p=.007). The military group tended to be less extraverted than the non-military group. There were no significant differences between the combat Veterans and non-combat Veterans.

Semi-Structured Interviews (n=60)

As interviews were completed, the recordings of each were transcribed and the transcripts were reviewed for accuracy and completeness and any errors were corrected. Cleaned transcripts were then uploaded into NVivo qualitative software to facilitate the processing, organization of information, and analysis. An index and coding scheme was developed based on theoretical concepts embedded in the research questions and precise and standard definitions and examples to ensure that individual coders consistently applied the codes to the narrative text.

Responses were organized within each area of inquiry based on the questions asked during the semi-structured interview. Similar responses were grouped together to identify categories and themes. These were used to create a report, which was shared with the interview participants and other interested parties through varying processes (one in-person group, two on-line webinars, and a two-part written report sent to all participants through the mail and online). The participants received a complete Report of Participant Responses and a Summary of Findings (see Appendix B), which summarized the longer report and asked for feedback from participants.

The goal of the feedback mechanisms was to gauge the accuracy of our findings and to determine if there was other information that we had missed that should be included. The Report of Participant Responses was then reviewed in light of information gained from these feedback sessions; this information is presented below and will be used to develop further presentations and manuscripts for publication.

Qualitative responses were organized into eight areas, each with a range of overlapping categories and themes. The following areas and categories were extracted and examples of each described below:

Table 20. Qualitative Interview Response Categories

Area	Categories
Background	Socioeconomic, education, background habits and values
Feelings and thoughts immediately following SCI	Feelings immediately following SCI, thoughts immediately following SCI
Path to current life and sense of flourishing	Pathway, adjustment process, turning points, high points, low points, current thoughts about life / attitude / outlook
Behaviors associated with successful adjustment	Working to maintain physical health, working to maintain emotional health, changing the environment
Things that contribute to feelings of happiness	People, activities, other personal factors, approach to life / attitude
Things that detract from feelings of satisfaction or happiness	Internal factors associated with their impairment and health, including psychological factors; interpersonal factors, such as the attitudes of others; environmental factors, including policies and physical accessibility.
Recommendations for those with new injuries	Interactions with healthcare providers, actions to take (as well as ones to avoid), things to understand or realize, perspectives to adopt / suggested approaches to life
Critical resources, programs, and policies	Information, programs and policies

Area 1: Background of Participants

In addition to the demographic information collected in the survey, participants also told us more about themselves during the interview. From this, we discovered that individuals with SCI who were identified as flourishing after SCI did not come from one specific type of background. They came from diverse areas of the country. Some were born in Michigan while others were from other regions of the country.

- *Right here in Detroit, Michigan. Yeah, right in Detroit, Michigan, bred.*
- *I grew up in New Jersey. In central Jersey.*

Some participants told us that they had moved around a number of times as a child. It may be that in doing so, they developed the ability to adapt to new situations – a skill that may have helped after their SCI.

- *I changed high schools every year. At the beginning of every year, I was a new kid in a different state.*
- *I used to live in every Southern state with my mother at the Air Force with my stepfather. You know, Georgia, North Carolina, South Carolina – I lived in Virginia, I've lived in New York...*

For the most part, our participants grew up in rural or suburban areas. The areas where they grew up may have impacted their relationships to other people.

- *Yeah, small town and, yeah, it was just a giant neighborhood. And I knew all the kids in the neighborhood. We all went to the same school.*
- *The friends I had ...set high standards for me ...and my parents sort of wanted me to—they didn't have a whole lot of money and I think they thought that if I'm going to be able to afford college—they wanted me to go to trade school, and even my dad had gone to business college.*

While many of the participants appeared to have grown up in supportive two-parent families, this was not universally the case. However, most of the individuals indicated that they felt safe and supported even if their parents were divorced. Relationships with siblings were also generally characterized as good.

- *Family support system in my younger years was very, very good. My parents got divorced after 25 years, so I was a college student when they divorced. So I had a two-parent household. Though we moved a lot, we were a family.*
- *When I grew up I was having a nuclear [family] – mother and father were married. ... We were really close. I had a very good childhood. In terms of when I was growing up, I didn't have that many problems. Went to school. I got along with my brothers and sisters. I have a younger brother and an older sister. We used to fight a lot, but we got pretty close as we got older. Oh. We had a lot of cousins. We pretty much grew up together, all of us.*

As evident above, many participants felt as if they grew up with strong family ties and a strong support system.

- *Chaotic. I remember a lot of yelling and screaming. My parents were divorced—my parents got divorced when I was 16.*

Even those who discussed having experienced more challenges growing up were able to identify positive influences on their life.

- *Maybe ... because I knew how bad my dad was, became an alcoholic, I didn't get much off my dad except operating equipment type thing. As far as the father figure, he was terrible. But as a man he was awesome but that was end of that. But [my stepfather] told me what a man should be. ...So he treated me fine.*

Socioeconomic background: Being able to adjust to SCI did not appear to be associated with one particular socioeconomic background. Some participants described growing up poor, while others were in the middle or upper classes. Even those with less income and fewer resources, though, described having “enough” and feeling as if their actions made a difference, both in their own lives as well as in the lives of others.

- *We lived on the east side of Des Moines, which is the poor side of town, but never felt want for anything even though we didn't have a whole lot of money.*
- *Upper class. I mean my dad was doing well at [his company] ... We never had to want for anything....*
- *[I grew up] during the Depression. My dad worked in a steel mill....*

Education: All of the participants graduated from high school or earned a GED. Some had attended college to varying degrees. Many of those who stopped after high school expressed doing so not because of a lack of intelligence but because they were not interested in school and did not apply themselves.

- *Just the normal problems. I was really a good kid. Um, I think I got a couple detentions here and there.... All the teachers liked me and respected me 'cause I knew what I was doing and I just didn't put the effort into doing it.... Anytime I was tested, [they'd say] "You're really smart. You just don't put any effort into it."*

Personality: Many participants described themselves as being outgoing, active, and social. Others described being entrepreneurial. A percentage of participants described themselves as athletes while growing up and appeared to associate benefit from that activity and role. Other participants just described themselves as active, particularly in participating in outdoor activities. Only a few described themselves as introverted.

Many participants described themselves as outgoing, active and social.

- *Well, I was just a fun-loving guy—still am [laughs]—and I just hung out with friends, did the normal things [like] party, went to concerts—what your average early 20-year-old would do.... I was working at a store and, um, had recently moved out, you know, and was just doing the normal thing, like partying all the time.*

Others described being entrepreneurial:

- *Back then all you could burn – I mean all they heated their homes with was coal. So when you heat a home with coal you got all the ashes, so everybody had a pile of ashes in their backyard, and there was a city dump which was probably about a mile or so away, and I would haul people's ashes for ten cents a load with a wagon. I'd put like two bushel baskets of ashes on it, and I got ten cents for hauling them to the dump. And the other thing, I'd go out – I cut people's grass, but I didn't make too much doing that, I got 25 cents an hour for cutting grass.*

Some participants described themselves as athletes while growing up and appeared to associate benefit from that type of activity and role.

- *I've always been an athlete, I played three sports in college and I had a scholarship offer for wrestling and football at one school. I could have played—I tried out and made the baseball team at [my university]. So yeah, I was always in athletics and I miss that a lot!*
- *So as far as that goes, the background – I had played pretty competitive ice hockey from the time I was 12 through college and then loved football. Like to watch football. Still play softball. Still play sled hockey. Did all those things growing up and always went on family vacations.*

Others just described themselves as active, particularly in participating in outdoor activities.

- *I used to be very active – very, very active. I liked to run around and liked to drink beer and hunt and fish. I would consider myself pretty active before the accident. I rode a bicycle and yeah, I was very active. Fished – I had friends that fished and we'd always go fishing on our days off and stuff like that. Then shooting, reloading.*

Religious upbringing: Religion played different roles for different people in this study. Some individuals were raised in religious families while others were not.

- *I grew up not having a whole lot of spirituality or religion in my life. ...So my mom and dad decided "We're not going to have our kids brought up in any certain religion; we're going to let them do what they want" because they didn't want us kids to go through anything like that when we were starting to settle down and start our own families.*
- *Well, I was raised up Baptist. Sunday morning, Sunday night, Wednesday, Tuesday prayer. The whole summer camp – the whole everything. But I don't know, there was so much of it that I just veered away from it when I got out of the house. It was always present – always aware, and I do believe.*

Values, skills and habits: Participants in our study mentioned specific values, habits, and lessons that they learned while growing up that they felt were important in making them the person they were. For some, these values were learned from their families; for others, it was the military that instilled them in them.

Accountability

- *Well yeah, I mean, they hold people accountable for what they do a lot more than the civilian world does.*

Ability to adapt

- *Well, some people look at things like "Oh geez, that's too tough, I can't do that." Well, I don't look at it that way, I look at it like – oh, there's got to be a way.*
- *You got to find some other way to do what you got to do. Like I used to run, be very active. Being in the military you have to be very active and then running and being all athletic and all that good stuff and then you have to find ways to substitute how to adapt to that way like hand cycling.*

Attitudes

- *Just the attitude that you can get things done and never give up and things like that. That's why I still belong to the VFW and all the guys there that – most of the guys I hang around with are Marines and we all had that same attitude. That's the Marine Corps attitude that nothing will hold you back and not to give up. Get things accomplished. That's probably the same in life working on these cars and doing all the other stuff is the training I had back then and your fellowship with your friends and colleagues and stuff like that. That's real necessary.*

Communication

- *I don't think I was ever a good communicator.... I wouldn't say that I was a bully, but I definitely would not back down and I think that was the result of not being able to communicate. So you have to make that transition in life and I think the military helped with that.*

Confidence

- *Yeah buddy, I went and got some plain clothes, so I've always done extra for everybody for that kind of thing, so I've always volunteered for anything that had to be done in the military but it gives yourself confidence, it really builds you up.*

Cooperation

- *How to work together, how to be a man, how to think for yourself, how to, you know, how to basically treat other people, how to live together in a – as much as I hate other people - learn how to collaborate with others and when you have to be right there with them all the time. But it gave me structure, it gave me – you know, a little sense of how to be polite, you had to – that's where you got your no sir, yes sir, yes, mam and that kind of thing, the whole that all comes from it.*

Coping Strategies

- *Improvise, adapting, and overcome.*
- *There you go the army taught me how to be patient. Hurry up and wait....*

Discipline

- *I think discipline and following authority is one of the things that stuck with me through the military.*
- *I also think the discipline [in the military] was probably just what I needed in my life.*
- *My dad taught me stick-to-it-iveness, self-discipline....*
- *You got to learn to take orders. If you are not the type of person who wants to take orders, you ain't going to make it. Because you ain't the boss!*

Goal-setting

- *You know, it is kind of like mission-focused, I guess you would call it, and then, you know, you kind of set a goal for yourself, and you aim towards it, and you work towards it, and sometimes when you get to the goal you are really not sure what to do, but, you know, that is kind of you work toward a goal, I guess, would be one thing with me.*

Independence

- *It was definitely a growing up. I kind of looked at it later and said, "It should almost be a requirement for every kid to go through this," makes them grow up real fast and realize that it's not just a big old game, it's real life. You've got to work, you've got to compete with other people and you're not judged by...like the famous Martin Luther King. You're judged by what you do, not by what you look like or who you know, for the most part.*
- *Yeah, I've always been that way. I—you asked if I had done sports and I have but they were more independent sports. Like I did track and cross country, not quite team sports, but I have done team sports.*

Improvise

- *Yeah. Improvise, adapt, and overcome. That's what they kept telling us [in the Navy].*
- *You got to make adjustments - improvise.*

Integrity

- *Teamwork, integrity. I'm a big person on integrity. Say what you mean, mean what you say, and if you say you're going to do something you need to do it, you know.*

Leadership

- *Lots of things. How to read people. That's the biggest thing, how to read people.*
- *Probably some leadership skills, because when you're running a squad you've got some things there and I guess maybe the most would probably be learning the different personalities of people and how to lead them; what motivates one person doesn't motivate another person, that you've got to get different people different ways to get them to do – get them in line to do what they're doing and try to pull them along with the group.*

Listening

- *I still remember the stuff today and listening to my doctors when I had to listen to my drill sergeants and all that kind of got me on the path to listen to my doctors because I always thought I had a better plan, but I don't.*

Organization

- *The way I keep things, the way I keep organized, the routines – kind of incorporated you know do certain things certain ways and all that and the results you get and all that are all valuable teaching tools and all that.*
- *I think I'm a bit more organized, a little bit more ordered. Like I said, I wasn't in all that long, but I do find myself organizing, especially supplies and stuff, kind of making sure I have enough of -- even at the shop here, the sandpaper and the paint, you know, I've got it all organized in cabinets and stuff, and I didn't used to do that before, and I don't know if that came from the military or just from necessity, but I do find myself more organized than I used to be. It used to be I, you know -- because I used to -- like I said, I worked on cars at an auto shop, I'd throw everything in the toolbox, and it was where it was.*

Perseverance

- *Well I think it was kind of reinforced that if you work hard and put your mind to it you can do just about anything and you will be rewarded.*
- *I can say in the military I did develop - and me being as timid as I was and going to the military - that might have even started some of my strengths as well because of how the drill sergeants would yell. They'd stomp, they'd - irate idiots as I call them, but at the end of the day when I figured it out I'm like "Okay. They're here to do a job and that's to intimidate us." So I developed mind over matter and that mind over matter literally has carried me to this point now. Whatever your situation is it is literally mind over matter.*

Relationships

- *I was just doing my job ... We were just doing our job like 500,000 other guys over there at the time. So your friends had a way from making you think you were special. But it was good comradery. I mean, we were tight, if that's what you means. The six of us, we were very tight.*

Respect

- *How to work together, how to be a man, how to think for yourself, how to, you know, how to basically treat other people, how to live together in a – as much as I hate other people - learn how to collaborate with others and when you have to be right there with them all the time. But it gave me structure, it gave me – you know, a little sense of how to be polite, you had to – that's where you got your no sir, yes sir, yes, mam and that kind of thing, the whole that all comes from it.*
- *But that was just because that was who they were, but I think I got out of – more out of what anybody gets out of a job in the senses that you have respect for other people you work with and understand the significance of the job that you have and you do it to the best of your abilities.*
- *And that's how they raised me is to respect people and so, yeah, I want to respect them in what they ask me to do.*

Responsibility

- *Yeah, it teaches me how to - you know my grandfather already taught me how to take care of myself and to be a man let's say. Responsibility, he just instilled responsibility. It just instilled everything that my family had already told me about responsibility, cleanliness and how to take care of yourself. I had already learned about weapons because I hunted and everything. They just instilled the things that my family had already taught me. ...That's why I say I was able to deal with boot camp and everything that people say they can't deal with people*

telling you what to do or when to go. I had been raised like that, organized. How you go to sleep at a certain time, you take care of your room, your area and things like that in general.

- *And, I think, probably more so the responsibility – and picking up rank fast you have a lot of responsibility. So, I not only had to grow up because it's time, but also to do that as a leader for other people.*

Survival

- *Oh, yes! Oh, yes, definitely. It played a big role. Because I been through a lot of obstacle course and being in this wheelchair is one obstacle course. It's like an obstacle course. You either pass or you fail. Because it's like going to basic training. Or you goin' Ranger School or Special Forces or, you know, Commando, whatever, Navy Seal, whatever, you know, you got to survive.*

Work ethic

Many participants displayed a strong sense of practicality and self-reliance. This was particularly true if they grew up on a farm or in rural areas. Of note, 100% of the individuals who provided feedback reported that they had developed a strong work ethic either while growing up or through military service.

- *And I think having a strong work ethic. I grew up working my whole life.*
- *But I was fortunate enough to be doing stuff when I was probably too young to be doing it. ...When I grew up, once you were big enough to reach the clutch pedal on the tractor well, you drove on the bailer, that's what you did.*

Area 2: Feelings and Thoughts Immediately Following Injury

We were interested in what participants thought and felt immediately after their spinal cord injury. Since it is sometimes difficult to accurately recall that type of information – especially given the range of years that passed – the information below can probably be best thought of as current recollections about thoughts (cognitions) and feelings (emotions) after the SCI.

Emotions and Feelings Experienced Immediately Following Injury

Depression / Sadness

- *Post-injury for like the first year, year and a half, I was pretty down in the dumps. I feel like I didn't know what to do, really confused, just worried about where I was going to go in life.*

Worry / Anxiety

- *I guess a little anxious about how – maybe worried about how it was going to affect everything.*

Uncertainty

- *I guess there's a lot of fear of the unknown and that's – you don't know what to expect. You don't know what you can do....And so I think initially you have that fear that you don't have that independence or freedom. It was taken from you ...*

Broken / Helplessness

- *Yeah. I felt just broken down. I know that I went into a – I was worried about my – well fiancé at the time. I remember being worried about that. like that was – really worried me, but I remember having those same feelings when I had that wound and I went to Chicago and I had to lay in an air mattress, air bed for an extended period*

of time until it healed. I remember having those same feelings, but they're more feelings of helplessness. And so maybe at a time when I felt broken, I just felt helpless because I didn't have a wheelchair at that time. I didn't have a brace, I wasn't able to get up. So I guess, for me, I wasn't able. You're someone who's independent, doing everything for yourself and everything in life, and then all of a sudden you can't do that. You just kind of feel pretty helpless I guess.

- *I was sad, you know, I cried a lot. It was kind of like well, we're in a whole process. I mean when you just – it was sad as much as anything else it's like god, I mean I can't – just a basic thing, I want to go down – walk down the driveway maybe. You can't do it, then all of a sudden you're in a world that's not set up for wheelchairs...*

Determination

Participants' determination, either to walk or not to give up, was tied for the most frequent response within this category on the feedback report.

Determined to walk

- *I never let it bother me. I knew I was going to walk, I was going to get around –*
- *Well, I can't tell you exactly what all I was thinking. At that time I was in a lot of pain and stuff so I was more thinking probably about the daily things and my daily routine and what I had to do and get strapped up with that turtle shell and trying to get some of my bounce back and then I pushed it hard for a year in therapy there, I was determined to walk. I did, but like I said, it wasn't functional.*

Determined not to give up

- *I didn't give up. Didn't give up. And I had – one of my biggest inspirations was my daughter. I mean, I wasn't going to be down because – I just got to stay strong because of her. That was probably my biggest inspiration right there, and, I didn't give up. I kept on doing stuff that I, believing now, I did stupid things that I shouldn't have done with that back brace on like picking stuff up – I was only supposed to pick up the newspaper but I was determined that I was still gonna do it, so I'm lucky I didn't get hurt again. But no, just – strong-minded, kept on going. That's what I did.*

Discouragement

- *Oh I don't know. Oh, there's times I get discouraged but never for long. Sometimes you get to a project that you just can't get your body in the right spot and I'll just have to go off and I'll say, yeah, let it set a little bit and I'll try something else, and then next thing you know, I'll think of some other way to do it ...*

Confidence

Of note, "confidence that I will figure it out" was tied for the most frequent response within this category on the feedback report.

- *You know, I was just always confident and trusted in God immensely. A lot of coping skills I learned as a life coach I was able to apply to myself and that helped tremendously.*
- *...I always volunteered for anything that had to be done in the military but it gives yourself confidence, it really builds you up.*

Feeling bad / sorry for family members / Feeling like a burden

- *Listen to your doctors. It's not over; there's everything that runs through your head that moment "what's going to happen to me?" I just keep a positive attitude and hang around positive people. It's best – It's all their personal experience, that's what happened to me. It seems to work, it's not the end. I thought it was. I thought I*

would be a – laying in there the snow and the first thing is I'm going to be a burden to my family. Someone is going to have to wipe me, feed me and all that crap and I don't want that. I don't want my family to – I think it's not all about me. It's about a greater purpose and I'm just a small part of a big hole. If I can be a part of it then I'll take it. Just don't quit.

Suicidal

- This sucks. I had contemplated suicide. I thought maybe it's better if I died. Your mind runs through the whole thing, 'What if I'm stuck like this forever? I don't want to live like this.' But I think for me it was just part of the thought process and then you obviously reject that.

Anger

- I was always angry. It's an adjustment you have to go through. Being depressed is one of them. You have to take your time. You have to go through a cycle, and then eventually accept it.
- I was really angry – I mean, really angry, that's why I said I scared the pastor ... I think because I didn't have nothing good to say to God or anybody else as far as that matter went.

Acceptance

- Immediate ability to accept being paralyzed and accept the fact that you're never going to walk. I wasted no time just, "Oh, I want to walk, I want to walk, I want to walk." I didn't really care about that all that much. Just teach me how to get around and be disabled and I'll be just fine.
- Well, probably a positive attitude. I mean even though I was hurt I still could do a lot of things. I mean it was not that, you know, life was ending. There were a lot of things I could still do. There were a lot of challenges going forth and, you know, I knew that, I accepted that. Being young, being physical enough I mean there were just a lot of things I could overcome; but probably the biggest part sometimes is to accept what you couldn't do. You know, the failures, you know, that things were locked out just because of that. Over the years, you know, things frustrated me like places with steps. I mean, you know, that automatically says "nope, you're not going there," so that bothers me.

Thoughts / Cognitions Immediately Following Injury

Negative / Stunned

- Man, I really did one over.
- I thought that I was screwed for sure.

Caught up in what you cannot do

- So that was one of my thoughts just that I wasn't going to be able to do that anymore. A lot of the post-injury stuff was yeah, focused – especially depression stuff – was focused on what I wasn't going to be able to do anymore. I was dwelling on that. I couldn't walk. That was when I was just negative and just in a shit mood basically. After I stopped dwelling on that and then I started realizing all the stuff I could do, that's when it picked back up basically.

Unsure / unfocused

- What in the hell does the future hold for me? How do you get about your life? You know, how am I going to get a job? I mean, everything I ever did before I broke my neck was physical. You know, my jobs were physical and everything I'd have was a physical person. You know, it was physical, physical, physical, you know, just – You know, and then that changed immediately.... It was, "So now how are you gonna go about your life? What

are you gonna do? How do you, you know – relationships. Are you gonna meet anybody, you know? Can somebody love you? You know." It's just a whirlwind of problems, you know, that seemed like they're huge problems and insurmountable, you know, at that time....And then – and you worry about it...

Worried about others

- *I was concerned about my youngest son and my grandkids because it was going to change everything so much – how it's going to change my relationship with the ones I love. I guess that's basically was my concern on how it was going to – I was more worried other people and how it was going to change our relationship.*
- *Oh God, my wife didn't sign up to be married to some gimp in a wheelchair.*

Confident that they will figure it out

- *But yeah, at first it was – I think at the very first, "Well, I can adapt. I can adapt pretty good. I can fight in the jungle. I can fight in the desert and I can fight in the mountains or I can fight in the ocean. So yeah, ... Sometime I get frustrated... But I kind of adapt and try and not take on more than I can do anymore.*

Focused on what needs to be done

- *And I can remember going back to [the rehab center] and probably wasn't as social as I normally was and just telling them, "What do I have to do today?" I remember my wife, at the time, saying, "What's your deal? Like why are you just – you go out there and you do this and then you're done?" I'm like, "It isn't that. I just want to get out of here. I want to go home and I want to just get back to life." She's like, "Life has changed." I'm like, "Yeah, but it doesn't have to be. It's a chair and we know what to expect. Let's keep moving."*
- *My thoughts after I got injured. Well, when I woke up and they said – and I think my wife told me I was – somebody told me I was paralyzed. I don't know who. And then I just said okay, what do I do next...*

Determined

- *I just didn't know what I was going to do in life, that's all. I was kind of in awe, but I was determined that I wasn't going to lay down and give up. I knew I was going to get up and do something and make the best of the bad situation. And I have.*
- *Well, I can't tell you exactly what all I was thinking. At that time I was in a lot of pain and stuff so I was more thinking probably about the daily things and my daily routine and what I had to do and get strapped up with that turtle shell and trying to get some of my bounce back and then I pushed it hard for a year in therapy there, I was determined to walk. I did, but like I said, it wasn't functional.*
- *... suck it up, you got a family. They don't like you but suck it up, you've got to deal with it. Worse you are, the worse you're going to be with them. Maybe we can fix it, maybe we can't but you've got to do something.*
- *Oh yeah, so you know immediately after I'm thinking holy crying out loud, what's happened here, you know? I mean I can remember falling, I can remember I never lost consciousness so I can remember the episode, I can remember everything...I know how fragile life is, I didn't have to crash in a blaze of glory to know how fragile life is, I knew that. But now it's actually happening to me, it's not happening to somebody else....So I thought that was a rather strange experience to kind of go through, and then as far as the being in the hospital, it was always then a mental fight to move, to know that this was not going to happen to me, I was not going to walk out – I was going to walk out of this place, I wasn't going to roll myself out of this place.*
- *Thought it happened for a reason. I know not many people could deal with this, but I understand that this is something I can deal with and I'm able to understand this. Better me than someone else I guess.*

Detached

- *Oh, after it immediately. It was kind of freaky. I mean, ... well, I'm just fascinated with how the human body works. It's just a freaking machine to me. Not that I'm irreverent of it, like somebody who like abuse a machine, like hurt their cars or something and drive it – No. I mean I'm in awe of the machine. I think it's really cool. So I think I approached the injury from that standpoint. I'm just was kind of like, "Oh, that is really weird. I cannot move my foot now." ...So that's definitely – that kind of outlook has definitely helped me, not that my injury hasn't been a downer, but it's that kind of viewpoint in life has kind of helped me deal with it. It's just a machine. Your body is a machine. Take care of it, you know, or do maintenance on it. It breaks down, you know. It's hard to upgrade it. We're working on it. But anyway, I'm sorry.*

Positive

- *I didn't really fret too much about anything. I guess I just thought, "Well, it's another hurdle I got to tackle." I didn't really – don't really recall having any negative thoughts about it all when it happened. ... You don't have focus on the negative stuff and I – that's kind of how I dealt with it. Just tried to look at the positive points in how things were going to change. And some didn't work out so well and others did. I mean, I wasn't scared. I guess a little anxious about how – maybe worried about how it was going to affect everything.*

Area 3: Path to Current Life and Sense of Flourishing

Participants described various pathways to their current sense of satisfaction with life. While some individuals talked about a gradual process, others mentioned specific realizations or events that served as turning points for them. In addition, for some participants, family members were key in providing the support and motivation to continue to move forward. Categories of responses reflected the path to adjustment, including turning points, high points, and low points.

Adjustment Process / Paths to Adjustment and Current Life

Need to learn patience

- *But I was used to mowing my lawn or doing things. I needed help getting things done now so I'd call people. Well, they have lives and they're busy too, "But hey, yeah, I'll get over there, but it'll probably be on Wednesday." And this is Sunday and you're like, "Damn, I don't want to wait until Wednesday. I want to do it right now." And so that was probably one of the biggest things where I said, "Okay. That doesn't have to be done today. What else can I do," and to move on. That was probably. That was a big adjustment for me because when you get something in your mind and you want to get it done and you're fixed on that and all of a sudden you can't do it because you just can't physically do it. You have to wait for someone else. That's like, okay, we'll get it done, but it's just not meant to be done now. We'll get it when we get it.*

One step at a time

- *Just take one day at a time. You know I think my thing is just one day a time because as soon as you're injured you tend to think you know, how bad is it going to be, how am I going to do this and all they need to do is like everyone else, just one day at a time and then you find it gets easier, it gets easier. Whether they get better or not, physically, it does get easier, you figure out new tricks and it can be very rewarding and so. But it's hard, I mean I've tried to help people who've been injured, I know there's a – I remember the feeling when I got hurt, I didn't want to be in that wheelchair because I wasn't going to be that way. And so it's doing that time and so just do it one day at a time and I also – forced people around them, keep telling these people, the people around them keep telling that person how loved they are, how valued they are.*

Finding a sense of acceptance

- *You have to take your time. You have to go through a cycle, and then eventually accept it.*
- *Oh, I think just acceptance. Accept what you got and do the best you can with what you got. 'cause there are other people that depend upon you.*

- This is something that you were dealt with this. Move on now. Make the best of it.

Learning what was possible

- I guess kind of regaining like a normal life, so to speak, and not letting the wheelchair affect me whatsoever when I think about going out and doing stuff. Just going out and doing it and figuring out.
- ...what may be possible, just like you know, people ahead of me, guys like FDR and you know, a lot of amazing people have done things with handicapped – and all of a sudden you think if they can do – they can run the country I can sure run my life.

Finding a sense of purpose and meaning

- Whatever you can possibly do to add substance to your life and help others, do that to give you—so that you, your life in your own mind is meaningful. And that you feel good about yourself once you're doing it. You're not going to be depressed if you do something to contribute. If you don't—if you don't feel you are contributing, you have to sometimes work it, doing something extra as much as you can because there's so much you can't do. Focus on what you can do, not on what you can't.
- I think it's not all about me. It's about a greater purpose and I'm just a small part of a big whole. If I can be a part of it then I'll take it. Just don't quit.
- "Why me? Why did this happen to me?" Sometimes the voice will come back and say "Why not you? You've got a story that someone else has to see. Somewhere down the line your purpose will come out of this," and I developed a purpose. My purpose I feel was to definitely help those that may have a disability as well that would like to move forward in life.

Taking responsibility

- So I take it there's a sense of taking responsibility... Well, it was my fault that I did the drinking and I bought the booze and then I dove into the pool. I mean, I—it just took responsibility for what I've done and—there—there's nothing I could change about it. It's—it's just like it's just something you have to learn that it is what it is.
- I took on the responsibility to do it. To get the job done.
- If you're going to be somewhat on your own, you have to take responsibility for what's—for what is, for the actions you—you choose to take.

Disconnecting with people who don't understand

- And finally you got to let things go, you know. It's like playing poker. You got to know how to hold 'em, know how to fold 'em. That's how life is. Sometimes, you know, you thinkin' you got friends, you know, your know 20, 30 years or whatever. Sometimes you have to let—I had to let a lotta people go to get to where I am. I mean, just to [inaudible] me and they just don't understand. I ain't got to 'splain that. I got to look out for [myself]. I want to live too.

Allow yourself to grieve

- Try to be positive, but it – going through their grieving process. You have to go through the grieving process and eventually accept it.

- *I've, you know, adjusted with the wheelchair, I've gone through probably all the stages of denial and sadness and all that but then you start figuring out different ways of doing things and you do something long and pretty soon it's the new normal, you adjust to it and go from there.*
- *You know, it's a lot of I can't, I can't, I can't. You know it's a tough adjustment at first for anybody I think and I think there is really just kind of a grieving period there where, you know, you feel sorry for yourself then your pissed off and, you know, eventually you've just got to decide to get on with it.*

Reconnect with who you are and pre-injury identity

- *There's a book – and I didn't read it but there's a great title, Christopher Reeve book, it's called Still Me. You know, the double meaning of still me, but also still – you know, so if you really enjoy the person – now there's sometimes if – easier said than done sometimes because if you're buddies with people because you all like to do rock climbing, well, then it's like okay, we can't do this much together but you find other things that hey, maybe you like doing because ultimately you like spending time together. So you just try to figure out certain things, and there's certain – a lot of activities, generally there's different ways of doing it. And most – you can do it somehow in a chair.*

Stay active

- *So, still do what I like to do. It just takes me longer. Little more frustrating at times, but – and I tell you, you got to stay active. I notice if I have a bad day, I sit on my butt, I eat, and drink a lot of soda, whatever, and the next day I'm feeling it. So, the bad – when I get bad day or a bad couple of days, it takes me a couple days to get back in the groove. So, that's why I try and keep going. Try and keep going.*

Identifying a meaning / purpose for the injury

- *But the big realization that turned me around was the good Lord slowed me down. I was working fast and loose, and he got my attention. So I got my hands back; was not supposed to. It's a real blessing, so I'm going to use it to its fullest.*
- *But I realize it's all got to happen for a reason...I got to make peace. I don't let myself get all worked up.*

Reading, learning, and keeping your mind active

- *But I think like in terms of – and this isn't spirituality, but, in terms of helping me like cope with, like a mental sort of thing to cope with my disability, it's really been my reading and my learning. I have a – I'm very passionate about that...And that, honestly, I know it sounds kind of odd, but that's actually been a real coping tool for me because it's – I just find it so fascinating to study about other centuries. I just find it so fascinating. And it, it keeps me so that my mind isn't constantly on my disability because it can be on your – I mean, if you want it to be, your mind can be on your disability 24/7 if you wanted, if you let it. Some people who are injured they find that they deal with it best by going into some sort of advocacy work, and that's great if that's how they deal with it. That's too much for me. I need to know that I'm more than just my disability.*

Avoid negative thoughts

- *I guess a big point would be is to spend your time thinking about what you can do, instead of what you can't do. Because if you just sat there all day and thought about the things you used to do, you can't do now, that would destroy you.*
- *If you get them into the attitude that everything happens for a reason and get them dwelling on the things they can do, rather than the things they can't do, they probably have a better chance of coming out of it.*

Need to move forward and get things done

- *The thing that helped me cope with it is just what you say is, “Who’s going to do it if you don’t? You’ve got to do it yourself.” If you’re going to wait around for everybody, it’s bad. Let’s just get out there and do it and be done with it. It frustrated me to see this barn that we’re sitting in here. I would have built this myself, but I broke my neck and I can’t do this no more. Same thing, I got a shingle roof and I’d go up there and do it myself – let’s get this job done. It has to be done. But I can’t do that no more. So you’ve got to go get somebody to do it. That’s the physical capabilities that you can’t do that anymore. Know your limitations.*
- *I started adapting things that I could adapt so I could do the things I used to do. I’ve just been going forward ever since.*
- *I was always going forward and most of the time I did what I wanted to do. I found a way around things. There were a few failures, but, you know, I never let it bother me. I just had to accept it and move on and it’s always been that way.*
- *Coaching taught me how to reframe the situation. It taught me that you don’t look back. You go here and then you go forward. So I didn’t have to spend a lot of time trying to blame and find fault and be bitter and I just knew better and I didn’t feel bad in my heart.*

High Points

Most of our participants reported experiencing full and meaningful lives. High points reflected the importance that they placed on family, relationships, activity, recognition and making a difference in people’s lives.

- *High points? Probably all the same things, high points probably – you know, faith, family, friends. You know, the ability to do things, the ability to do work I love, I love having my own little business, I love being involved in my kids’ lives. You know, I love coaching, I love – I love being able to contribute. I guess that’s – you know, love for the memories I have of great parents and siblings, so...*

Family

- *Really fortunate to have a family of friends in good health.*
- *My prayers were answered when I got—got to see my kids grow up. She got to grow up to 16.*
- *Well, I guess the wife’s one – the biggest high point. Then the grandkids. I try and take care of them and get them squared away ...*

Friendships / Romantic relationships

Friendships and romantic relationships were also important.

- *The friendships I’ve developed, the achievements I did and made both as a professional and a personal individual, the lives I’ve touched and influenced both positively and negatively, writing my memoirs down about doing things like that, and what a good life I’ve had. It’s been good, paralyzed or not. I’ve been cut down to 2% of the man I was before, just muscular ability and then cut that in half again 30 years later and taken away and fighting back and getting some of it back each time. Still maintaining what I call independence and running my own life and making my own decisions and living alone independent, proud of that.*
- *Um, high points are seeing the friends that you know are your good friends, seeing them stay and...and knowing you have some incredible people in your life.*
- *I don’t know. Having a new girlfriend is one. ...And, I don’t know - I’m always happy. I’m just a happy guy. ...I don’t get down that much. It’s not just - it’s not worth it. Stress isn’t good.... I’ve always been that way. I’m just the most easiest, go-lucky guy you’ll ever meet.*

Sports, recreation and similar activities

Many participants mentioned sports and recreational activities as high points in their lives. These included competitive sports as well as activities that allowed them to just relax and enjoy life.

- *High points for me have been racing stock cars. People just don't see the wheelchair. Lately, it's been the [outreach group] thing where we take on some pretty good challenges. Engage people into the outdoors, trying to get them to see, "Hey, there is a life beyond whatever problems you have, but you just got to look forward, and you got to learn. You got to know that there is something there," and that's what we try to provide.*
- *This is my first year playing on the wheelchair basketball team. So this is another high point in my life.*

Education / School / College

For some participants, continuing or completing education brought with it the opportunity to connect with people as well a sense of self-worth and accomplishment.

- *College, for sure. Both like – it was the most – I made some best friends that I'll have for the rest of my life that are just tons of fun.*
- *The high points? My schooling. It was something I'm proud of. It took a long, long time to get through. I felt like I was in school forever doing that, and finally finished up, like I said, two years ago. I couldn't go back. I just don't – I love, love to learn, but I just – I couldn't go back to doing homework again, any of that kind of stuff. I just don't have the stamina for it anymore. But I'm proud of that.*

Making a positive impact on others

One high point that was both explicitly stated as well as implied by many in many of the narratives was how our participants valued making a positive impact of others.

- *I think it was really neat because they definitely don't have the same opportunities that I have had and like for example I went to their school and they all were asleep on the floor with just like little mattresses next to each other, and so I think it was neat for them to see there's a couple of us there that were in wheelchairs, like they're able – they're often seen as less in their society, so I think it was neat for them to see like us as like leaders going over there, that they can do pretty much whatever they want to do. So for sure I think that it was highly positive.*

Home / Building a house

- *... building a house is probably one of the better highlights of my life. We designed the house after going through a bunch of different people's homes that were accessible, taking bits and pieces of each home that we liked and kind of incorporating it into this house. I have a – again it comes back to family and friends. I've got a brother that – or I've got a brother and a brother in law that are builders. Another builder that's an excavator. We have friends that donated material and time to help build the house. I mean if, like I said, if it weren't for friends and family, I have no idea where I'd be at right now.*
- *As I said we have the lakeshore which is Lake Michigan. My favorite past time is to go to Muskegon to that lake. It is breathtaking to go there. My peace is there especially in the spring and the summer when the ice melts and you can go out there. It's beautiful. It's just breathtaking. I get a peace when I'm out there and that's what I can do. Writing my poetry and I don't know I just feel like I'm closer to God for some reason when I'm out there.*

Employment

- *But getting back to work at [my job] that was very important. That was a highlight of my life.*

- *In my career, here at [car manufacturer], I've been here a little over 30 years. I've had numerous jobs. But a couple of the high points are when I was in public relations, I was the manager of a child safety program But I get most of my satisfaction giving back. That's just the way I was raised. Give back to the community.*

Travel

- *I think really though, besides that, highest points of my life have been my – and I have to credit my parents a lot for this too because they worked really hard to do it – is my being able to travel.*
- *Other than that, high points, I think some of the trips that I've taken have been really fun. I did a cruise a one time and other times just road trips to Florida. I went to New York and the Adirondack Mountains. Yeah, there have been just some fun trips and things that I've done that have been good.*

Low Points

Participants within this study discussed the various low points that they had experienced since their spinal cord injury. While some of those were directly related to their injury, others appeared related to losses, hassles and frustrations that are common among the general population.

Spinal Cord Injury itself

As mentioned, the spinal cord injury itself was mentioned as a low point by some, but not all (or even the majority) of participants. Comments included:

- *Breaking my back. That's definitely the biggest disappointment.*
- *Obviously getting injured was a low point, but after I got over it which I think I did pretty quick, probably about 3 months, you know, that was pretty quick I would say for that kind of thing.*

Other participants articulated specific factors associated with their SCI that they struggled with.

- *The only time I felt low post-injury is just that first year or so. After my injury I just felt like the world was spinning around me. And I didn't know what to do until I started to get kind of a game plan together and realized I guess I could live again and didn't really feel low anymore.*
- *Well, the lowest I ever was, was when I broke my back not knowing what to expect, and not from me. More from my wife because she didn't – she was not into that bike and she would say every day, "You're going to get hurt. You're going to get killed on that thing." "Oh, no. It'll be fine." And it happened so that was probably the lowest point that I felt, but it was for her really because, at the time, I was like she didn't sign up to be married to some dude in a wheelchair, and nor did I knew anything about disabilities or chairs or anything like that.*
-

Aging with injury

- *Now there's frustration with aging and the injury where they combine together because the injury was incomplete. And so over the last couple of years, I've lost a lot of the feeling that I had in my lower extremities and stuff like that. It's a combination of the injury and then age compounding it.*

Hospitalization / illness/ surgeries

Secondary conditions, as well as injuries and other illnesses that occurred after the SCI also seemed to be associated with low points in people's lives.

- *Um, being hospitalized, nursing home, sickness. Little stuff like that.*

- *I'd say low points are probably just not taking care of my body like I know I'm supposed to. Like I stated earlier, I just had a flap surgery at the beginning of August. And I knew what caused it. I just didn't take the time to take care of my body. So, it really wasn't a low point. Then I did have a pressure sore like 2 years after that, so that was a , but it was costing me time –being up and around and possibly being able to do things. So I had to pick and choose events I wanted to go to or if I wanted to see a friend or go somewhere. I guess the low point, too, because I had to lay in bed for like 3 months would be just not listening to my body and taking care of it the way it should be.*

- *Some of the low points, when I have a lot of pain.*

Feeling isolated

- *Not having anybody to talk to, or not feeling like you want to discuss anything or see anybody.*
- *Well, some of the low points is thinking about the things I want to do and can't do and sometimes not having enough people around. Not having enough people around makes me reflect back on things that I don't want to think about. Other than that I'm okay.*

Decreased functioning

Participants mentioned difficulty with mobility associated both with the original injury as well as with aging with SCI as one of the specific losses associated with the injury

- *Yeah. Aches and pain and little thing, like I get a hard time. It takes me 20 minutes to get my shoes on and that's frustrating as heck, but you know. I got to do that – low points. And when I can't – I'd like to do things sometimes, but I'm not capable. I can't do what I used to and that gets frustrating.*
- *I remember after being in the hospital for three and half, four months – and I came home and I went from this end of the house to that end of the house and I came back to the door, and I realized I'd lost my purpose. I couldn't clean the house or cook meals or take care of my family anymore. And I really sat there at the door thinking, "Can I go back? Just let me go back to the hospital where there's more room and people." Just something to do besides – really I was lost.*

Sometimes the low points were associated with factors associated with living with SCI and the lack of awareness, assistance or accommodations of others. These included hassles with insurance companies, problems with aides, and disability-related employment issues.

Frustrations associated with impaired physical functioning and needing assistance of others

- *The low points inevitably surround the aide situation. New aides that don't show up; that's my biggest frustration. Aides that will not be flexible enough to cover each other and yet want to be covered when they need it. The struggle was dealing with aides, scheduling more so than anything is a bummer for me.*

Disability-related employment issues

- *Another low point of my life was when I broke my back, I'd been with the company almost five years and the director of our group held a meeting and I'll quote what he said. "[Name] no longer fits the image of a young [car manufacturer] professional. I hope he goes away." So that really pissed me off a little bit. It hurt my feelings hugely, but it really pissed me off because he doesn't know me. He never took the time to know me as an able-bodied person, let alone as a disabled person and he went out of his way to make it a little tougher.*

Missed opportunities

- *Low points. When I wasn't able to go on our senior trip ... because that would have been just too difficult and I was too tired and just – yeah, in high school.*

Frustrations and hassles

- *The state - the very first thing when you get hurt Social Security does – deny your claim; paralyzed from the neck down, they denied it. Submitted an appeal thing, whatever, ... The federal government says that money that's being paid to my father for taking care of me is called a "difficulty of care" payment and that is tax-exempt income. The state of Michigan says it's not tax-exempt income and they give you a 1099. If you don't report that state, non-taxable income, then your 1099 does not get entered into your 1040 and then your 1040 doesn't match what the IRS says you earned.... But, last year, the IRS changed the instructions now so you enter that into your tax form and attach a note and you get tax-exempt; because most states and the IRS realize that that "difficulty of care payment" is about one-third what it's going to cost to keep in a nursing home.*

Lack of accessibility

- *The only thing that caused problems was the actual physical limitations. Some places are less accessible, and some places are just not accessible by the wheelchair.*
- *Oh, the low points, oh, „like now, just before when you go to a party or something like that, or house parties, I don't like going to house parties because then – is that because you have to ask somebody to get you up inside the house. You always got to think when you go in these houses, I have to go to the bathroom, where am I going to the bathroom. Sometimes you can't get into the house.*

Healthcare providers

- *Once we knew what was going on and once the doctors, I will just say had their heads up each other's ass. I'm not exactly thrilled with a majority of the doctors on that particular team.*

Finally, for some participants, low points were factors that did not appear to be directly associated with the SCI – things like problem bosses, bad marriages, financial hardships, and poor health or death of family members.

Bad marriages

- *So it was very lucky and then I got married probably late, 34 maybe, and then I had a baby and then I went through a bad marriage and so, that was tough. And then I remarried and went through another bad marriage so I've gone through two – and those were tough.*

Financial issues

- *Low points, I think they're every day, I mean still to this day fighting, you know, since [my wife] was the major breadwinner in the family...and now it's gone. So our salary, the salary coming in, the income coming in this house has dropped by 75 percent. And nothing else has changed. So I'm trying to figure out how to rob Peter to pay Paul.*

Grief / Loss of family through death or divorce

- *The low points were definitely the loss of my grandfather and my divorce and obviously becoming paralyzed. The divorce was probably one of the hardest situations to deal with and primarily because you feel like you were the one responsible for that, which I know isn't the whole truth. But you know it takes two and I wasn't perfect and I accept my faults in that. But just trying to think of what else.*

Employment issues – not disability related

- *I lost a job once. That was a low point. That wasn't due to the injury or anything like that. Just typical life frustrations like everybody has.*
- *My low point, actually was my last six months at my job... I had a new boss who was just a tyrant. There's been a lot of turnover under her. She was just a miserable individual. I hated going into my job every day. I was just – I hated it. Just terrible. So really, it wasn't a reflection of my disability. At that time, it was just dealing with my boss.*

Adjustment Process / Path to Current Life

Participants described various pathways to their current sense of satisfaction with life. While some individuals talked about a gradual process, others mentioned specific realizations or events which served as turning points for them. In addition, for a portion of participants, family members were key in providing the support and motivation to continue to move forward.

Steady / No real changes

- *I think it's been pretty steady. As time went on I've learned different ways to do things and I do most of the things I did before but it takes me longer now.*
- *I think it's been a pretty straight path.*

Gradual process

- *I don't know if there were any turning points. I think it was more just a gradual – you know, it was different then all of a sudden if you get hurt in an accident you know, you go from boom one moment. In my case it was kind of like a gradual down and then gradual maybe up a little bit, then stop. So I had I guess time to adjust but no, there wasn't. I don't think there was a turning point just – you know a little victory is when I realize okay, I can drive, or I can get a house that's set up, or I can still do the business. There's a lot of things I can't do but once I realize there's a ton of things I can do then it helps. But I can't speak for one particular moment.*

A series of choices

- *Everything leads to a point where you are in your life. What can I say? It's just a series of choices with me, even on a daily basis or every little thing changes your direction in life. So yeah, I can look back on some major choices and things, things that I didn't make very well since my injury. It's pretty much focuses on my wife, because she – I was just in so much denial because she was an alcoholic.*

A process of hard work and determination

- *Hard work, perseverance I suppose. You just got to - you know anything worth having or being involved in in life you've got to work at it. I'm the same as everybody else. I'm just on wheels, you know.*
- *The biggest thing is determination. You can't do something, you figure out how to do it. Like I said, determination. You're determined, you've got to do this, you know?*
- *...After my accident... they saw my determination and I welcomed it with open arms because I know that literally I have to fight for myself; some things good, some things bad.*

Turning Points

During the interview, we specifically asked participants about decision points – if there were times that their thoughts or attitudes changes dramatically. While many participants denied experiencing these, others recalled specific events or realizations which shifted their perspectives.

Recognition of own ability and strengths

- Um—I guess it was when I would finally do something and not be stubborn and say I can't do it. And--and realizing that just do it and realizing that you can do it. That would be a turning point.
- High points? Probably all the same things, high points probably – you know, faith, family, friends. You know, the ability to do things, the ability to do work I love....
- My ex-wife used to say that it was my God-given gift, that I could fix anything electrical. If it was broken, I could fix it.

Changes in perspectives and approaches

- No, just deciding that I can't sit around and just be a little crybaby about stuff. Just get back to living life and just do what you want. I don't know. I don't know – I don't really have a motivational sentence to say that. Just making the decision that I'm not going to sit around and feel bad for myself that I'm going to get back to living and having fun and enjoying every day like I did throughout the rest of my life.
- Consciously thinking that I would not allow the wheelchair to limit what I did with my family / my opportunities
- The biggest thing for me about going anywhere, I didn't want anybody to see me in a wheelchair. I felt pretty much inferior, so I didn't for a while. I just wanted to kind of stay here and try to figure it out. That wasn't the right way to go on. Once I decided that "Hey, I'm alive just like everybody else. Only everything I've got to do is got to be totally different than the way I used to." Once I come to that realization and I wanted to get back into what I used to, then I had to start back and say "Okay, how are you going to fish?"

Small steps / Gradual process

- Well yeah. I mean, I used to love to kayak. I decided to go try that. So, I made that decision to go try it. I know that I need more help than me and an aide. There has to be people there. I went for a glider – just things I'd never done before. And I'm going to try to make the decision to stay active and do what I want to do – go figure it out. If that's what you're – the answers you're looking for. I don't know. I just made a decision that ... I'm not going to die five years into my injury. I'm going to carry on. There's a lot of life left to live and that's the decision I made I guess.

Sports

- Turning points. Oh, turning point is when I decided to go back to hand cycling. That was a turning point.

Independence / Moving out on own

- Turning points? Maybe one thing was moving out on my own. And I'm real grateful for that because many people with spinal cord injuries cannot do that. But I'd grown up – grown up – stop. No. You know I'm lucky enough I'm able to have the ability to do that. I don't have to somebody stay with me 24/7 because I can do a great deal on my own. Not everything, but a lot of stuff on my own. So I think that was a turning point for me. Yeah.

Injury / Disability itself

- You know, yeah, I guess I would say the biggest turning point was the instant I hit the ground and became disabled because, at that point, I said, "All right just teach me what I need to know. There's no way I'm going to walk again." I wasn't one of those people that for years and years and years all they want to do is walk. I mean, I see so many people, "All I want to do is walk. I don't care about doing anything, I just want to be able to walk." Well, 99% of those people are going to walk. They need to figure out what they're going to do in life to make them

happy. And if you continue down that path of I'm not going to do anything besides wanting to walk again, you're going to be hugely disappointed because there's no cure for paralysis, at least not now and probably not in my lifetime.

Employment

- *Yeah. So really, the first day – I was off work for three months – so first day back to work, that was a turning point because I didn't go away and I had to face the same people – the same guy – that didn't want me. So that kind of turned a little bit. But the biggest turning point between the crash and today, without doubt, was like five minutes after I crashed and decided to move forward.*

Proving others wrong

- *Yep. My junior year in high school. I remember later, towards the end of the year, they brought me in to talk about what classes I was going to go to my senior year and about what colleges I was going to apply to. And all of them were sub – just below my standards of colleges [laughter], and I made it a mission of mine for the next year to get all As and to get accepted to U of M. So then that next year, I took a full schedule and I took the AP classes and did what I would have been doing before my accident.*

Increased social comfort

- *I don't know, I think that, you know, it took me a few years to get adjusted where I was really comfortable, and hanging out and being a lot more social and stuff like that. Kind of once I got out of high school I kind of became a lot, you know, talked a lot more, because I was kind of a quiet person back then. I still had a lot of friends I hung out with, but kind of just expanded my friend base. I really, I think I just, what I don't know, changed everything, in just hanging out with different people and different perspectives on everything. It just got me to where I am.*

Wanting to make a difference for others / impact

- *Yeah, it was coaching. It was at this school coaching in the early 2000s that – life was good and all that kind of stuff, but for where I am now, had a kid cry and tell me what an inspiration and all those kinds of things. And I, just at that moment, knew that I needed to get out of the job that I was in and go back to school, so I could teach and coach, and try to have that kind of impact.*

Spirituality

- *Well, I do think that – I was raised a Catholic and I always struggled with my religion, because I really oppose some of the things that the church stood for. And I think spiritually that's very important to someone who goes through something as traumatic as a spinal cord injury or, you know, any other serious disease or... And I guess I found a different form of spirituality as I went through this. And I think that was really important in finding peace with what happened.*

Motivated / Importance of family and friends

- *Just like I say, family. It takes time, over time. Like they say time cures all and you deal with things, become better with things.*
- *So because of my speaking up for this situation I feel like I have to kind of lead the way or set a path for others to follow.*

Motivated by opportunities

- *For me the turning point was the opportunities to work, to just work, and basically being able to say that I have accomplished being able to go to work from my wheelchair. When I was working a temporary job I never missed*

a day. I always shoot for goals for myself, something that I feel reachable within this situation and I do my best to try to make sure that I tackle and bring out all barriers. Any barrier that is set before me I try to find routes around them from knocking on doors or trying to figure out what is the next alternative. There has to be a way.

Current Thoughts about Life / Attitude / Outlook

While we selected participants based on a general sense of well-being and feeling as if they lived a purposeful life, we also felt that it was important to get a little more information about that specific attitude or outlook. The responses below summarize what we heard.

Positive / Good / Life is good

- *Very upbeat. I have a positive outlook. Play the hand you're dealt. I do the best I can.*
- *I think I'm super positive. I think if you ask anybody, I'm positive and optimistic about everything in the future. I know we have highs and lows in life, but its life. I don't know. I really enjoy living and having a good time. I don't know. Yeah, I'd say overall I'm optimistic about everything*
- *So there's a song by the Pretenders that Chrissy Hines sings. The part of the lyrics is, "I've got a smile for everyone I meet." That's what I try to do. My outlook on life is really good. Maybe in four, five, or six years I'll retire, but I love what I do now so I'm not in any hurry to get out of here.And so that's my outlook on life. Is hugely positive. There aren't many nights when I just sit home and do very little. If I'm not out riding my bike or playing hockey, I might be up at mic night at The Tap, having a couple beers or something. But my outlook on life right now is good. It would be great if I could fix my neck and get my hand to stop falling asleep all time, but the rest of it is quite good really.*
- *As we talk, I think life is good. Sometimes I had to swallow some bitter pills. ... I swallowed it, see, and God ain't gonna put no more [on my back.]*

Desire for a family and a good life and do what you need to to get there / SCI as speedbump

- *...that I kind of want to have the same life—I want to, you know, have the same life I—I had growing up and give that to someone else and just be loving and caring. Um—I guess my outlook in life is just—get a job, I mean, just get a job, fall in love and have a family and be happy. That's—and deal with everything that comes in between. Um—that—that really hadn't changed, that—that had nothing—that never changed with the spinal cord injury. It just kind of put a speed bump in it....*

Feel thankful / lucky / grateful

- *It's always been a good outlook. I'm a little more humbled. I call it a rebirth, actually. You know, we have a tendency to take life for granted. Even though I was pretty sad about a fresh divorce, I still was pretty much in a good place. Then the accident came along and it was one of those wow. I was around these people that had these complete spinal cord injuries and it just, it still makes me just so grateful for how lucky I am. I guess I'm somewhat humbled by how fortunate I am and so grateful. I think about that constantly. I have a lot of time alone because I am alone and a lot of that time is spent being grateful for what I have. Trying to figure out how to make it a little bit better.*
- *Be thankful every day. Not a lot of people in my condition are living in a home. Most of them are living in a nursing home. I'm thankful every day when I wake up, just to wake up and open my eyes. People die every day, and I'm still living. He's terrified of the nursing homes. And I have my wife and son too. They're the ones that keep me going.*
- *I'd say good. I get along good. Like I say, I can do a lot of things that other people can't. I feel lucky about that*

because other guys are worse. I've seen guys doing this with a wheelchair, and I don't have to worry about that. My upper half's good. I can get around.

Optimistic / Hopeful

- *I was always optimistic. It hasn't changed. I go exercise when I can, three days a week and just keep living. Living life.*
- *You know, life is good. Again, not being in pain contributes to being able to feel that way. I mean, I see you know, a future from myself, like I say being a productive member of society, having good relationships the potential for a marriage, you know. I'd like to experience that again. And I see potential for it, so my outlook is definitely hopeful and good.*

Things the same – may take a little longer

- *Like I said, I do everything normal like anybody else would do. It might take me a couple of more minutes...
...So that would be the only thing...*

Realistic / day-by-day

- *Kind of – I wouldn't say it's way positive, but I wouldn't say it's way negative either. It's pretty realistic, I think. But I don't think that it's really like negative or anything like that. I think it's pretty positive. There's certain things that I would like to be doing now that I'm not doing and that is in part because of the disability. Not all, but in part because of it. And because the disability limits your choices on things. Sometimes that's frustrating so it's kind of – I don't know. It hard for me to say, "Oh wow, it's super positive." But I – I'm not – it's not negative either. It's just kind of day-by-day sort of.*

Life is not fair but you deal with it

- *No, life's never fair when you expect – what you expect life to be it'll turn on you. It'll turn on you in a heartbeat. I'm a living, breathing stuff of that, it slapped me down more times than – but I keep getting back up.*
- *No, life's not always fair....It's probably pretty much what you make it.*

If you want something, work for it and earn it

- *My outlook is – I mean, if you want something, work for it and earn it and go get it. I mean, I think that's just kind of the life I live. I know for a fact that my wheelchair has hindered some things in life. There's no doubt in my mind. But I think that – I also feel that's my responsibility to tear those barriers down for people.*

Don't take anything for granted

- *My outlook on life is real positive. As I said earlier, I take nothing for granted. I did before all the time. Now, like I said, there's never a day – never in my life would I wake up and be like, "Hey, this is going to be a great day." But now, after the crash, like I said, I don't take anything for granted. Life is pretty good and I know so many people here that hate what they do all day long and they just bitch and complain and brings everybody down. It's like it's just not a good thing.*

Everyone has their struggles

- *[Life is] not fair, but I think that's kind of given. It's just – but I'm also a strong believer that no one person's situation is worse or easier than the next. We all have our struggles and we all have things we deal with and no one person's is worse than the other.*

Happy / Enjoy life

- *I mean I enjoy doing what I'm doing. I mean I enjoy going to work all the time and now I have a lot of hobbies. I am very happy. I mean got a good wife, family, all the kids, everybody is doing well. So I'm very pleased.*

- **Taking it as it goes**

- *I describe it as taking it as it goes I guess.*
- *My outlook on life is just go with the flow.*

Experience regrets but not letting them consume him

- *Oh, the longer time goes on, it gets better, I guess. I'm still disgusted whenever I start thinking about it, it's like, "Why did I dive off that dock," you know? If I just had that ten seconds back things would've been a lot different....Oh there's regret, yeah – can't deny it. I really wish I could get up but I also don't plan on sitting like this the rest of my life because I know they're working on it, I just wish they would hurry up faster.*
- *Well, I wish my spinal cord never would've happened. I think it'd been, probably own my own business by now. But, overall, I wish it was a lot better – wish it would've turned out differently, but, gotta be happy with what you've got, so I'm gonna put it at that – that's it.*

Pessimistic / Cynical

- *Good for the most part. My general outlook is usually good. Do I always see the best in people? Probably not. I'm probably more of a pessimist as far as people go. I generally think most people are scum when given the chance, but my personal outlook is good.*

Life is life

- *I don't know. Life is life. You just get up and do it I guess. Yeah, I mean there is no -- I can't -- I don't know if it is from the injury or just getting older, but you kind of go from I'm going to do this, I'm going to do this to I need to do this because tomorrow's are getting less and less, I guess, so that is about it. It is not anything terrible or grievous, it is just I guess I'm starting to realize that I need to start -- instead of planning for one day, you start doing so...*

Best you can for yourself and God

- *My general outlook on life? I live the day the best I can for the Lord, and look back and see what I've done for him, and look forward to what he's got in store for me. You only can live that way. I guess it's positive most of the time. You got to deal with the things that come your way in a positive way, and not get down about it. That's about all I got to say about that, I guess, I don't know...*

Fair / Decent

- *I can't say it's great. Like I say I need to address the health problems I got and other than that, I have wonderful sisters that help me out. So it's basically pretty decent for what... for the circumstance....Yeah, there's definitely things that I could do that I can't now. So yeah, it's changed quite a bit.*

Area 4: Behaviors Associated with Successful Adjustment to SCI

In general, participants identified three overlapping categories of behaviors that seemed to be associated with being able to do well or flourish after SCI. These included behaviors associated with maintaining physical health, behaviors associated with maintaining emotional health, and behaviors associated with changing the environment.

General Responses

Working to maintain your health

- *So, in the other side of the house there's like a little gym area. I work out almost every day. Diet – very, very important. I definitely like to eat so it's very important that I do try to maintain a healthy diet most of the time. Especially, in the wheelchair, I've noticed having a bowel and bladder routine, it's – I know I still drink alcohol and hang out with the guys, go fishing, do those things – still do those same things so I have to be more cautious, I think, sometimes where I don't think other people understand – friends do now. I mean, it's been – I've been in the wheelchair probably 12 years. But those things you pay – that you – I guess you take for granted, I can't take them for granted if that makes sense. I have to be aware of what I'm doing.*
- *I do my annual physicals. I do go to my doctor appointments. So I do preventative maintenance of my health. Very blessed. No high blood pressure, no diabetes, no high cholesterol. All of that is intact and I think that is what allows me to have a healthier lifestyle and that's why I don't consider myself sick and that I am malfunctioning because my mechanics don't work as well.*

Keeping interested and involved in life

- *Oh, just look for the—look for as many things as you can do and do them and feel good about them, um, as you can. You know, continue. Whatever you can possibly do to add substance to your life and help others, do that to give you—so that you, your life in your own mind is meaningful. And that you feel good about yourself once you're doing it. You're not going to be depressed if you do something to contribute. If you don't—if you don't feel you are contributing, you have to sometimes work it, doing something extra as much as you can because there's so much you can't do. Focus on what you can do, not on what you can't.*

Keeping your mind active – reading, learning new things

- *Well, going back to working, physically working, has helped my brain work, or getting off the drugs helped my brain a lot. My brain was just not functioning. So, going to work, practicing working, that helped. Reading – well, I can't turn pages – the reading keeps my brain working a little bit.*

Learn how (and who) to ask for help

- *I want to be independent and I want to do it myself and then I'm frustrated because I have [to ask for help] I guess early on. It was back in rehab when I had to ask for help.... realizing that, yes, I have to ask for help when I realize I have to go to the bathroom. And that's, I guess, realizing that I needed to ask for help when I couldn't get up and go to a [restaurant? Restroom?], turn on a TV or things like that. So it was early on in rehab, learning—but I still have trouble with it.... I think people who are more willing to say, "Nope, he's disabled and so I have to do this," and so they'd go yes, so I would ask them. And then there are other people who say, "No, you can do it so you need to learn how to do it on your own." So I definitely know that game of who to ask and who not to ask.*

Problem-solving / Figuring out what can be adapted and doing it

- *A lot of things – a lot of things are, for me – they were just figuring things out on my own.*
- *I don't know. As far as a new situation or whatever I always go back to my engineering-type things and try to figure it out. Like I say, my mind works very mechanical. So I think our kids today, even up here, the very simple things, just simple levers and pry bars and things like that that you can do to get something done, they don't learn any of that. Just simple little things, it's simple to me that you see somebody else struggle with it and... But I was fortunate enough to be doing stuff when I was probably too young to be doing it.*

Changing the environment

- *That I did adapt? I mean, it started out from moving in here. I didn't even have a ramp on the deck or even the front porch, or any of that kind of stuff. So, yeah, I started out with building ramps. Are you talking about with construction-wise because that's what I'm going to tell you about basically. ... Accessibility-wise, I guess I'll go back in the house. I added in the floors. To help out with my shoulders, I widened my bedroom doorways down there. I opened up my bathroom and did like a roll-in shower and added a Jacuzzi tub and stuff just to make it really [nice] and easy to get around. I moved the washer and dryer to a place where I could easily access it. Just basically making everything wide and open, and easy to get around in a wheelchair, I guess.*
- *Well, I made a lift for tractor... Very early after my injury, we've got a walk-out basement here and it's a pretty steep hill to go down in the back and not – I could make it with a wheelchair but really difficult, so I took an old lawnmower and whacked it in two and took the front wheels and put them on the back wheels and put a platform on it so I could ride up and down the hill on it.*

Setting goals

- *I think they need to keep setting goals and targets. That is something that I would do. I would set goals, you know, I'm going to lift my foot this far, you know, I want to take three steps, I want to take ten steps, you know 20 steps. ...It was real important - I kept setting goals and I would have usually a goal beyond the goal, you know, two goals in mind. You know this one and I would already know what the next one might be and I kept rolling with that.*

Relationships /Social networks

- *And go out and be social. Still be friends with your friends and keep in contact with them and have a—that's one good thing about social media, now you can do that with Facebook if you, uh—three guys I played football with and I email probably every day about something during the football season, anyway. And we use our football numbers instead of our names when we sign. So ... we email about every day because we talk about the Iowa game and I tell them about the Michigan game. Just, you know, keepin' in contact and having lots of friends.*

Behaviors to Optimize Physical Health

Being proactive

- *Constant maintenance and preventative care...So take charge of your life and don't smoke, exercise, eat healthy and you will be healthy, strong, productive. ...Take control of your own health and learn about it and how to treat. Communicate with your doctor and nurse or aide and make your needs known. Remember you're number one because you've got to have your health to be a good partner.*

Listening to medical advice

- *Doing what the doctors told me. Keep my physical activity to a minimum, stretching. I go to a chiropractor, which relieves the stress because I'm always in pain, so my muscles in my neck are always getting tense and all that shit so – he helps me with that – went to a – what are they called “massage”. A friend of ours took massage therapy school to become a therapist and all that, so I was a guinea pig for the first 2 years after my surgery and all that. That really helped relax me, tension wise and all that.*

Develop a routine or structure

- *Well, the only thing I can think of is I'm structured. So like the cathing and taking care of my bladder and the bowel program and I really just about taking my meds, the meds I take, and I wash myself. I was really worried the first while about skin condition so I wash my clothes, and I have had no issues on skin conditions, and UTI's one every two years or something, as far as a urinary tract infection or something like that. I just don't have many day-to-day problems.*

Exercise

- *I exercise. I can say this, over the past four months I have not been as avid at it as I usually am. I will do at least six or seven miles on a track, pushing. However, because I am not able to get on the - well during this time bow because it is dark when I get out of work - I have a tabletop bike that I get on and ride for about an hour. I try to do it at least three days a week for my health. I know that it is very important especially in this particular situation that I have to try to remain*
- *I go exercise when I can, three days a week and just keep living. Living life*

Diet

- *To manage my health? Try to eat right the best I can. I set patterns for myself - I still have problems with my bladder and bowel incontinence. So, each and every day I have a pattern, when I have to go the bathroom, whether - cause I can't feel if I have to go or not - so I have to use a pattern and go every particular time each day.*

Skin

- *I'm really cognizant about avoiding skin issues, like on your bottom that a lot of people in wheelchairs get. I always sit on an air cushion. I, you know, about the only time I'm out of my chair is in bed or in a car. But, I never sit on anything hard or if I do get in my recliner I'm good about doing pressure releases and stuff because I understand that once that stuff starts that's pretty much the beginning of the end. You're never getting rid of it because you're always sitting on your bottom.*

Bowel and bladder management

- *You know, it's - that thought is never far from your mind, because you're - it's almost subconscious but you're always aware of your situation. Partly because even like bladder or whatever, I keep track of when the last time I went to the bathroom, when I probably need to go to the bathroom again, when - how much fluid am I drinking. Bowel movement, when did I last have - you know, so it's all that but then also where am I going, like I'm going Dallas this weekend, so you've got to - I know I'm flying, I know I need to be there a certain time because I'm the first one on the plane. So I think it's a daily thing of in your mind, you're planning all these things, of what you need to do differently than I wouldn't have done before. You know, I never kept track of the last time I went to the bathroom, you just go with it... But when you know you can't control it as much you just plan these things. So it's constant, if you're going - if I'm going someplace I haven't been then you have to plan it more, but then you also have to let it go, like - it may not go as planned but it'll be okay, no matter what happens, I'll be okay. If I can't get handicapped seating at the sporting event, I'll live. You know, so all these things. If I can't get handicapped seating at the sporting event, I'll live. So it's all - it's kind of like you do the planning but then if it doesn't happen it doesn't happen.*

Pain management

- *I do pain management where I meditate and closing the gate on pain and a small little thing I can block out... in a half hour I'm supposed to take some kind of pill that is supposed to make my pain, but I don't know if it works or not.*
- *Yeah, I think if you have the pain, investigate everything you can as far as medication, if it's therapy, physical therapy or mindset or a counselor - if you're having a hard time, get a professional... that knows something about what you're dealing with.*

Fatigue

- *Fatigue, I tend to take naps every afternoon for 45 minutes to an hour, which helps tremendously. They're pretty important. I don't always take them, but about three to four times a week, I do take them, take naps.*

Range of motion

- Right. Right. Yeah, and that's the – I think, you know, for me that's the biggest thing that I do is the range of motion, stretching exercises morning and night.

Weight management

- I think that managing my weight is important.
- You know, I try to eat right and I was heavy. I weighed almost 400 pounds and I had bariatric surgery because the doctor told me you won't live to see 60 if you don't do something, so I went and had the bariatric surgery and lost about 250 pounds because I want to stick around awhile.

Medication management

- I try to keep on top of my medication.
- Oh, I weaned myself off of all my medication, so I'm two years now without a drug. So I don't take anything. I don't take Tylenol. I don't take glucose, and even for my workouts, spinal cord medications, I weaned myself off of those. It's been two years. It took me about four or five months to do it, but I'm pretty happy about that. I'm real happy that I'm not on any meds.
- That's what I do, you know, take my handful of medication. It's real important for me to try to keep my pain from, you know, getting too high.

Blood pressure

- This blood pressure issue is because of the spinal cord injury and it fluctuates so much and it is dangerous when it is terribly low or terribly high because my heart is just working too strong and does damage to the heart. So for the last two years it's just been fluctuating all over. When it's really high I have to stay in bed. When it's really low I have to stay in bed because it's just not safe for me to be running around when my blood pressure is really high or really low. So that's been a bit of a struggle.

Behaviors to Optimize Emotional Health

Talk to / work with mental health professional

- And over the years if I've been struggling mentally or if I've been stressed out, I will go see some kind of mental health professional if I need to.
- That's why psychiatrists and psychologists have their jobs as you know, to help, if people do need help adjusting to a new situation you know, there is no shame in that. Because it is a traumatic event, and it's not just the person that it happens to. While the person that it happens to is the kind of object of, and suffers kind of the brunt of the accident, you know, it very much does impact the family as well. It's going to change the dynamic, but if you work at it, you can get things to a new normal. Not the "old" normal, but "new" one.

Support groups

- Well, some of them I think, focus groups and stuff would help them. I don't think it would help me much, as far as focus group unless you have a focus group where I was getting information about various things other people had done that I would like to do but as far as – once you got their attitude fixed I think the rest will pretty much take care of itself. If they've got the proper attitude. And I think sometimes the focus group helps people's attitude, that some people have to expose your soul say as such and talk about things and in order to get somebody to build them up.

Meditate

- *I'll meditate and I'll calm my thoughts or my pain levels. Mostly I learned to meditate to control my pain and then in that I learned to - it's almost like I can - somebody said, "Oh, you're just hallucinating."*

Be aware of / in touch with your feelings

- *I think the most important thing is being in touch with yourself, being in touch with yourself and your feelings... I would advise a lot of people to just realize those things. If you don't settle with yourself first you won't be able to settle with anybody else. I found that out the hard way. If it's not sitting right with me it's not going to sit right regardless of what anything else would come into the picture.*

Importance of social and emotional support

- *...You come to realize that everything is going to be alright as long as you've got a support group. If you've got a support group and it's the right group everything will work out.*

Prayer

- *Pray because prayer does work. A lot of people don't believe that, but prayer does work. God will put you with the right people for the right things. That's been my biggest support.*

Return to work / school

- *I guess for help to transition into a career, maybe help a person to find his career that's going to interest them that they're able to do and then to get them – because I think the easiest thing to do after post-injury is to not think that you can make good money and get a real good job and stuff like that, and to keep them, I guess, from going – not that greeters at like Wal-Mart are bad, but just to keep them out of that mindset that they have to go to that job, that they can still achieve anything and maybe pursue education. I guess that's really [inaudible 0:17:30]. So that's one of the biggest things, I guess, is to help maybe get them to achieve their educational goal too.*

Adaptive sports

- *I think that activities, I'm partial to sports, still very involved in sports and I really enjoy them, but I think that even if you aren't a sport person that getting involved in those will lead you to avenues of whatever activities you do like and I really think being active makes you healthier, which makes you happier and so that's kind of my advice.*

Keeping your brain working

- *Being able to learn. My intellectual curiosity has helped me a lot and had given me a lot of happiness, I think, in dealing with it too.*

Focus on the positive / Avoid the negative

- *You know, my family, my, you know, my wife, my family, my – the environment, my ability to work, to be productive, to pretty much do as I please within my, you know, constraints. I mean, I can go on for two hours about things that, you know, that are positive and happy things. I mean, sitting here looking out this window right now and, you know, leaves are changing and, you know, winter is coming, and you know, we have a nice home. It's made for us, you know, we have no needs....Have never got a hungry day in my life, and I don't – You know, I have worries about the future, about retirement, but they're not any different than anybody else's I guess, you know when you get to the stage, there is just – And we have books, we have a coffee-maker, a dog laying here. I mean, I can – I mean, there's just a ton.*

Area 5: Things that Contribute to Your Feelings of Happiness

When asked about the things that contributed to feelings of happiness, most of our participants mentioned people in some way – people in general, family members, or friends. The attitude or the approach to life that people adopted was also mentioned by many respondents. These are the general responses or themes that were described:

People

People in general

- *I love people. Care about people. I want to be there for my friends too. I'm real sensitive to some things. I love my family and I enjoy watching them grow and move forward. I love people and a strong faith that give me real certainty in life. Kind of simple.*

Family, particularly children including adult children and grand children

- *God and my wife. I guess the way I take to things. If it hadn't have been for them two I wouldn't have been as positive as I was like I said. The grandkids kept me level; kept me busy doing something. I was always occupied. I have five kids and all of them were there. I have five kids ranging from 31 to 39. So they was always there.*
- *What contributes to it? Number one - I'll tell you what the number one thing, that contributes to me staying strong? Is that girl that you've seen just grow up back up to college. That's my number one thing that kept me strong, I'm going to tell you that right now. That goes all the way back to the beginning of my injury. It's to make sure I raised her, was the first step, now it's just – me saying "Hey, good to see you grow up and can't wait 'till I get some grandkids."*

Networks of friends

- *What contribute the most? My friends. And I wish I could say my family but they're kind of missing.... So it's mostly my friends. Those are the people in my life to keep me going. And I'm so respectful of them.*

A good support system / siblings who are willing to help

- *I think support system. I think having a good support system. I'm very lucky I have a really good family support system. I know that a lot of kids who, or parents, who end up having a disabled child – at least in the time that I was a kid, and things might be better now because there's more education now. I don't know. But at least in the 70s, in the early 80s when you born or if you had a disabled child the divorce rate was so high. And it was usually – no offense, but it was usually the men leaving the wives because they didn't want to deal with this imperfect child. And so, luckily my dad's not like that at all. And so, my parents stayed together, and not that things weren't rough. I'm sure they were and everything, and they had a marriage like everybody else where there was good and there was bad to it and stuff, but overall they've got a good solid marriage. And I think that helps a lot is having a good support system. Having siblings that are willing to help you too. That's really important.*

Others with SCI

- *You know, I think everybody needs to be allowed their grieving period and their time to be pissed off, but pretty quick somebody has got to kind of say, "Hey we got to get on with it." I think meeting someone in a similar position is very helpful because it really helped me meeting that guy...who was in a similar position. A little worse of an injury, but still doing well. I think it really helps to talk to other people that are in the same position that have got through that initial hard period. I think that really helps. You know, at first I thought, you know, "Oh I don't want to go to that support group meeting. I'm not like them, you know, I'm not a cripple," although I*

was. And I had to kind of come to the realization of it and it helps to meet other people and talk with other people in a similar position.

Approach to Life

Sense of purpose

- *Family, friends, sense of purpose, having someplace to go, keeping busy, feeling a sense of self-worth, being able to just get in and out of your house.*

Accomplishing things / Getting things done

- *To be able to achieve things. That's one question they asked me when I was in therapy. They said, 'Well, what do you do for fun, recreation?' I said I work! What do you mean – that's what you do for fun? I said yeah. I feel better when I can look back at something I accomplished and not just sitting around. So that's what I do, I try to accomplish things.*
- *For me probably having goals and having something to work towards.*
- *Oh man. Well, doing chores and getting them done. I like that accomplishment where I plan to do something or we me and the wife get together – I plan and do something, and completing in a respectful amount of time and without breaking too many things.*

Taking on challenges and being able to overcome / Pushing yourself

- *Taking on challenges and being able to overcome. Doing some things that I never thought that I'd be able to do. I hate talking in front of people, but that pushes me out of my comfort zone. I still don't like it. It's just people are leaning on me from all angles in our group to get things done, where the people who walk around don't want to accept the responsibility. So I don't mind that challenge. I hope we're doing it for the right reasons, and as long as it's for the right reasons, we're going to be blessed as we have been.*

Having goals and something to work towards

- *So, if you think you're going to walk again, that's a good positive goal. Chances are you're not going to walk again. If they found a cure for paralysis today, I wouldn't be able to walk. I've been in a chair for 25 years. My legs are so atrophied, there's zero muscle left in my legs. So, anybody that's been in a chair for five or six years wouldn't be able to walk anyway because they don't have any leg muscles. So the quicker you get over that and move on to "all right, I'm disabled, I'm cool with that. I get great parking spots now. What can I do?"*

Recognize impact you can have on your own life and its outcome even with injury

- *I guess my outlook on life that I've had all along. Yeah, I mean I've known people that, you know, have passed away due to, you know, drug and alcohol abuse, being unhappy in their lives. I guess, you know, one of the things I've always felt like is we don't control other people. We can control ourselves and we can, you know, choose who we want to be around with, who we want to be around and, you know, having other people that are living normal good lives around you I think is a good thing. I think it's good for me....And again, being around people that are, you know, also of the mind-set that, you know, you can improve your circumstances whether it's economically, physically, mentally, spiritually, relationships, you know. Being around people like that is important too.*

Not dwelling on paralysis / accepting impairment and moving on

- Happiness or satisfaction of life. Now, all together composed is that you have to accept what happened to you. I can't go back and say, feel all sorry for me, I got hurt. Oh, poor me, I got hurt. I can't do what I used to do. You can't let this define you. You got to find some other way to do what you got to do.

Faith

- My spirituality. Knowing that I can do good for others and just being the person that I am. I'm always looking for the positive in anything and everything and everybody. If I hear something, when I hear something that's negative, I have to look at whatever positive is in that and change it around.
- Well, of course the Lord being there for my guide, and my help, and my provider. The wife that he's given me to live a life that's an honor and glorifying to him. I guess that's the biggest thing that contributes to my happiness, and I hope to the happiness of my wife. We just [Inaudible: 00:44:04] and we kind of just pray that we be the best husband and wife for each other that the Lord will have us to be. That's all I think about that.

"The drive" to prove people wrong, to work, to contribute / Determination / Persistence

- My drive now was to just prove people wrong who had the idea that people with disabilities can't contribute to society. So what drives me is working – just being able to say to people who don't know somebody with a disability that despite the physical differences, I can be just like everybody else. Work, pay taxes, have a girlfriend, family, participate in society as opposed to just collecting disability and sitting at home. So that's what drives me.

Positive attitude

- Well, probably a positive attitude. I mean even though I was hurt I still could do a lot of things. I mean it was not that, you know, life was ending. There were a lot of things I could still do. There were a lot of challenges going forth and, you know, I knew that, I accepted that. Being young, being physical enough I mean there were just a lot of things I could overcome; but probably the biggest part sometimes is to accept what you couldn't do. You know, the failures, you know, that things were locked out just because of that. Over the years, you know, things frustrated me like places with steps. I mean, you know, that automatically says "nope, you're not going there," so that bothers me. Other than that, I don't know.

You are responsible for your own happiness

- ...You're responsible for your own happiness. You can choose to be happy, you can choose to be appreciative of the things you have, or you can choose to wallow in your own self-pity, I guess, too, you know. Sometimes you got to go there. You'll go there sometimes. We all go there. I mean, its part of being human. If you've never been there, I don't think you're being truthful. Everyone's been there. I've been there and I'll probably be there again. ...But what makes me happy is I don't dwell there or I don't end up having to stay there very long. It's usually a reason or something that brings you out of it. You realize or recognize or you just take action.

Activities

Keeping busy

- My wife, family. Part of it is that I'm a geek. I like tinkering with stuff. I've got an office area set up where I've picked up the hobby of making some jewelry. I got myself a laser so I can monkey around with creating some patterns and different materials or marking stuff to make this or that or whatever. I've got enough to keep me

busy. It's nothing that is going to be like a Tom Swift type of environment, but it's close enough where I'm not going to get bored and I won't let myself get bored. I will always find something to keep myself occupied with or I'm sure I will come up with some decorating ideas that will require some thought into it. So we keep ourselves busy.

Volunteering / Helping others

- *Like I said, volunteering. I go out to – just actually last week.*

Wheelchair sports

- *I'd definitely say that like sports had a big impact, I ended up playing, it made me want to do more, I ended up playing in college, so it was motivation and I got scholarships that was nice, paid for some of my schooling. I definitely feel like that was a huge part and I feel like it connects you with other people that do have disabilities.*
- *And I'm very active. I play wheelchair tennis, not so much anymore just because of the time that it takes. Our team, we practice twice a week, but it's at night during the time that I work so I can't make the practices. In the winter time they do have a onetime day practice that I can usually make it to.*

Being as independent as possible

- *Like even me being in my situation, me being in a chair. I still drive. Still cook. Still clean, mop, you name it. Move stuff around. I lift weights, attached to my wheelchair to be exact.*
- *I guess my independence makes me happy. Um, just—I mean, just knowing what I can do on my own and—and doing it on my own, being my own adult, I guess.*

Doing what you enjoy

- *I just think doing what you like, finding what, like anybody, I don't know, finding something that you're really passionate about and it's like doing that and just like you can do whatever you like regardless. I've never really thought much about being in a chair, like making me happier. I'm happy, I've done a lot of these studies and stuff. I don't know, I feel like the biggest thing is – especially for people that are injured later is just introducing them to normal – what they did before. You can adapt most things – it might not be exactly what you did before but you can adapt most things and they'll probably be reluctant to do it because it won't be exactly the same but once they realize that there's so many things they can do once they've been injured....*

Return to pre-injury activities, such as hunting and fishing

- *...Being able to just get back the little things that I always did pre-injury like hunting, fishing, and stuff like that. The further post-injury I get just regaining more of that stuff back. I guess kind of regaining like a normal life, so to speak, and not letting the wheelchair affect me whatsoever when I think about going out and doing stuff. Just going out and doing it and figuring out.*

Being able to get up and around and do most things that need to be done

- *Simply being able to get up and get around and do most things that I want to do or need to be done. In terms of getting around, I may be a little sore at the end of the day, but if I want to close the pool, I can close the pool. If I want to take the Jet Ski out, I can take the Jet Ski out. If I want to go for a walk or a bike ride, I can go for a walk or a bike ride. The only things that I would probably be otherwise doing wouldn't be very many other things*

other than just maybe like water skiing or snow skiing and that might be two or three times a year even if I was doing it. So that part is not much of a loss.

Work you enjoy/ Employment / Being productive

- *I think the most important thing was to be able to continue to work and be productive. I think it's – You can't surround and dwell on what isn't there. You get dealt a deck of cards, you got to play on. And I think you just have to accept that, that this is the hand I got dealt and I have to make the best of it. And I think being able to work and be active physically, find other enjoyable things like kayaking, that I could do physically for enjoyment to replace some of the things that I lost. I just think you can't – And you just have to get on with your life. And I think being able to go back to work as I said, go back to work and contribute was important.*
- *Part of what keeps me happy every day is I've got a great career to go to.*

Other Personal Factors

Good disposition / personality

- *I think the personality I was born with has helped a lot, who I am and the way I look at things helped a bunch. My family foundation, but with the injury and stuff like that, my wife – it was a support kind of thing like that. I had my best friend and confidant, and all of those things, all in one always with me and always supportive and stuff like that. She could see and somewhat understand my frustrations when I had them. And then just going on and having a family, that was a positive thing.*

Dog

- *Like what – the top thing, I think it would be my dog, honestly. I feel like that would be the one thing that makes me the happiest, or has made me the happiest.*
- *Well, the dog is definitely a big help.*

"My land"

- *I do it with happiness because I look back on my land and my cabin and my pond and my – the wild life and all the good stuff. It's kind of cool, but I go up in the morning, I sit down there, I face the west, sunset sets over there, rock parlor every night and you know, sun comes up over there and I get to see all that ... the land is my happiness*

Spirituality / Faith / Religion

- *It's definitely my faith. You know, it's just definitely my faith and my perspective that this is - it's just a journey. It's not the destination, it's just a journey that I'm on.*
- *I think my faith. I'm real certain and like beyond believing. It's more knowing to me that God is real and alive and I've seen way to many things to question that. So my faith number one.*

Family foundation / how raised / parents

- *Well, most I think probably starting with the foundation that I had. Good better or indifferent I had a good foundation in family, and still basically do. I think everything's based on a foundation, whether it's your family,*

your home or whatever, building your house or your marriage, your life is based first on a foundation, so I was given a good foundation for that. Again, that's not something I had control over. So I think – all those types of things come from that beginning, having parents that loved and cared, they weren't the best but they certainly weren't anywhere near worst or bad, they just – they are who they are but again, they had an obligation and they stuck with it, which made us in a sense sort of stick with it and understand that.

Financial resources

- *I'm not rich, but I'm not financially strapped either. I can kind of do whatever I want to do, go where I want. That money can't buy you happiness. Without a doubt it cannot, but it doesn't hurt sometimes being disabled. They told me this in the rehab too. They said, "Being disabled is expensive." And it is. I mean, there's some stuff that insurance doesn't pay for. So, I mean, there's lot of things.*

Area 6: Things that Detract from Your Feelings of Satisfaction or Happiness

Possibly because of the way that we selected participants for this study, most people were not focused on the negative things in life nor dwelled on what detracted from their happiness. When asked, responses tended to fall in three general categories: (a) internal and impairment related factors associated with their impairment and health, including psychological factors; (b) interpersonal factors, such as other's attitudes; and (c) environmental factors, including policies and physical accessibility.

Nothing really

- *I'm not sad. I'm not sad, I'm not angry. In general, I'm happy to be alive. I'm happy to be here. I have no major complaints on nobody, with nobody, with life.*
- *No I can't think of anything.*
- *Take away from my happiness? A lot of homework, I guess. I don't really know. That's about all really. I don't really have anything that takes away from my happiness, I guess. I feel like I'm super fortunate. I don't really have anything to complain about.*

Normal stuff – not associated with SCI

- *Probably my own pettiness or my own frustrating of – you know, I get frustrated with kids, – not really wheelchair related, I mean I'm so used to that but you know, if I got a daughter that's acting like a knucklehead that gets frustrating.... just the normal stuff.*
- *Right now, I think it's just getting committed. I've got to set priorities and I'm a good one for not being able to say "No" if somebody asks for something....That's my biggest problem with – I got too much on my plate.*
- *Usually, it's outside sources. I get annoyed on Facebook when people post a lot of political and social stuff. I just want to see how my friends are doing. I don't want to know what you think of a political candidate. I just – when people aren't nice, that's what brings me down. Everybody just try to get along and be nice to each other. So those are the things that bother me.*

Internal Factors Associated with Health and Impairment

Impairment-related factors

- Take away most from my happiness? Definitely my condition. I really feel held back. And that's a struggle for me, because it's like a dragging anchor on my life. And it doesn't matter how positive I am or like how much steam I pour on it's still there every second of every day of my life. So definitely that, because I feel like I can do anything in life, but you really can't.

Pain

- My pain. My pain. I put my pain way above being a paraplegic. Even if I couldn't move anything the pain is far worse of a disability.
- Pain – actually I would say pain is the number one thing. I take medicine for my pain. I could take a lot more, but I don't want to because then I'm just – it just knocks me out – or it doesn't knock me out, but I don't want to take anymore medicine because of the effects of it. So, pain in the number one thing.

Self-image

- And self-image, body image, I think that's kind of hard too. I'm getting over it more so now that I'm getting older and realize that I'm not really as cool and as handsome as I really think I am or ever was, but – and my kids tell me, "Dad, you're fine. You're fine. You're fine, Dad. Don't – you're not fat. You don't look like a slob." But I've seen people in wheelchairs and think, "Gross! You smell like piss and you're filthy." And I think that's one of the big factors why I take so long with my bowel program because I don't want to be that guy.

Limitations on mobility

- Mobility is definitely an issue. I know they're making leaps and bounds they say. When I got hurt they said, "Oh, Christopher Reeve, they're putting so much time and money into this program that he's developed, and you'll be walking in ten years." Now it's been 15 and I don't. I still can't feel anything. And maybe one day I will walk. I don't really – I don't look at it that way. I don't anticipate ever doing that. Maybe somebody with a damaged spinal cord. Maybe someday they will. I'm sure someday they will. But probably not in my lifetime. But I don't have just a damaged spinal cord. Mine is completely severed. So, there's a lot more work to be done before that or before that happens to me....

Poor health

- My health, my health....
- Illness. You know that's, always got that – I mean that was a big thing for us though. We didn't have to worry about one thing but we had to worry about pet scans and sleeping the day before those and you know, I mean there was like nothing like you ever experienced in your life when you're waiting for the results of a pet scan. I mean that's just pure torture.

Increasing functional limitations – things are getting harder

- Some of the things that are more difficult for me to do now than they were before, and my quality probably isn't as good. I do quite a bit of welding, and in the winter especially, and it's a lot harder for me to get my body in position to do the welding, so when you're reaching and with bifocals it doesn't help. My quality isn't quite as good as it once was, so that bothers me. To see my quality slip a little bit.

Frustration with the lack of independence / dependence on everyone

- *The dependence. I have to depend on everyone for everything. I have to have aides in the morning to get me up, to get me dressed. The basic things. Just the dependency. And not that I have learned not to mind asking people for help, but you still are dependent on them coming through.*
- *The occasional frustration with the lack of independence. I know I had said earlier, usually I can find somebody to do stuff with me, whether it's a family or friend. But as I've gotten older, just that drive to be independent, to be able to do things on my own. It gets on my nerves a little more when I want to be able to go do something and I can't. That's gotten to me more....*

Nuisance of needing to carry around supplies

- *I'd say very little. Just the nuisance of having to carry around a bunch of catheters when we go away for three weeks. That's a suitcase full of catheters basically and diapers. I think that the nuisance associated with that is probably the biggest thing and just the idea of having to use the catheter, not having a normal bowel and bladder. And that also means having the erectile dysfunction, which is probably one of the strangest of the lingering effects, is probably one of the strangest. And so I'm still working on that part.*

Neurogenic bowel and bladder

- *My bowel program. When that's not going right, stuff isn't going right.*
- *The whole bowel/bladder routine is a pain in the ass. I hate to say this because every time I do say something like this, I jinx myself, but I don't have bowel or bladder accidents. Very rarely I do. I do if I'm sick or I'm stressed or I eat something bad. That tends to screw things up. But for the most part I've got it under control. But it's just so time consuming. That's the worst part. It's a good two, two and a half hours a day, every day out of my day going through that*

Erectile dysfunction

- *I think if I could have some of the intimacy I could have had with my wife as beforehand would have resolved some of the tension at times. We've since learned to work around stuff like that, but because of the injuries part of that is no longer a no-go at this particular point. That human touch is always in the back of your mind because you want the rest a little bit, but you really can't.*

Attitude / Negative perceptions (and people who are negative)

- *Negativity and laziness. ...If you're a negative person get out of my life and I'll run them out. I have had enough of your negativity.*

Own negative thoughts and tendencies

- *Um, I think holding onto mistakes I've done. That takes away from it. Like I said, if I make a mistake doing my work, that I hold onto that feeling a lot and so I still do that. Um, you could say I struggle with trying to let—let that go.*
- *I guess if I feel too sorry for myself, only if I let it. I mean, you're in control of your happiness... It's easy to be unhappy if you let yourself be unhappy. Sometimes I am a little disappointed. I'd like to be a little more of a macho guy that I used to be, but I can't.*

Relatively minor nuisances and frustrations associated with physical impairment

- Some of the frustration with the – one of the things I think of is when my wife and I got married not being able to dance kind of thing. Things that would've taken away, would be like when the kids grow up could go play catch. But I wasn't like going to go run them down, and do some of the running around and things like that. Did it a different way. Those things would've added frustration. Oh, the frustration, you know. The daily frustration of wanting to do something and not being able to figure out how you can do it or – I think that's probably the worst thing.
- Well lots of times other people, I mean there are a lot of inconsiderate people in the world that -- take away. I don't know I mean I don't have any real specific examples that bother me. I mean, you know, you just can't walk up to somebody or hug somebody, you know, those kind of things.
- Just like doing things that I couldn't do and asking people to help me do things, things that were so simple before and nowadays, you just got to wait and get somebody to help you and kind of show them how to do it where you expect them to know it and they don't. And you got to explain every step to them. Things like that are a little irritating sometimes

Interpersonal Factors

Divorce

- And like I said before, the divorce, that's what nearly killed me. I didn't think of suicide or anything like that. It's just that was the most stressful, heartbreakin trial of my life. I look back and I think of the spinal cord injury, thinking, "Wow, that was really bad." But I don't think that really compared to this – to the divorce. So that really kind of sucked.

Lack of partner / relationship

- I don't have a girlfriend or a wife and I enjoyed being married. I was married 11 years. It was the most amicable divorce on the planet. We just really didn't love each other. So we got divorced.

Concerns about children

- Watching my son struggle takes away a little bit. He really is trying hard to do something with his life but he's lost. He changed so much after my injury and that worries me some. It takes away from my happiness because I want him to be happy and I watch him just struggle daily. He's lost and I don't know how to guide him. I mean, I can talk, but I never went to college and never really did any of that and I just don't know how to guide him through what he needs.

Suffering of others

- I don't like seeing other people suffer. You know, like I said [spouse]'s mom and dad just passed away, you know, I don't – I mean, I don't think anybody likes seeing that, but that takes away from my happiness.

Perceptions of the public/ media

- I think public perception on disabilities. I think media. All of that stuff is – makes things a lot of – it makes things very difficult. ...They don't show people in wheelchairs that often at all and I think our society has a long way to go with that kind of stuff with public perception. They don't show them being married, they don't show them as a family, none of that stuff. So, it gives the impression that it doesn't happen. It gives the impression that it can't happen. And I think if they would change the way they do some of that stuff it would help some of the public perception.

Inconsiderate / negative people

- *Maybe, some of the coworkers I work with, you know. You just deal with people. Dealing with people that aren't happy sometimes. But it don't take away my – nothing can take your – It's a choice. They might get me grumpy, but they don't take away my happiness. Once again, it's a choice: You can be happy or you can be sad or you can be grumpy. It's the mindset that you have.*

Environmental Factors, including Policies and Physical Accessibility

Insurance companies

- *What takes away? Insurance company ... I guess the struggle that you get with things that I need, like a van where I could work or more money. Definitely more money. Disability does not pay well. Struggle with the bills. I guess that – the struggle trying to get things I need to go farther. Because the more independence I gain, I can't utilize any of it because I hit a roadblock.*

Lack of accessibility

- *So it was hard and you've got all those emotional things; how am I going to do this, I was, you know, my family was in a two-story house, we're in the second floor bedroom and it's like well that house doesn't work and all of a sudden you're there, you're – and you can't fix it yourself so you feel like you're trapped and you can't help and people are relying on you.*
- *You know the thing that's taken away from me is the thing I miss is walking across the curb. You see people, instead of meeting them on the sidewalk and then got to go to find out how way to get this way. People just – I mean, it's part of nature, 'cause you didn't actually go anywhere 'cause you're walking on curbs, grass, any kind of thing or just any kind of obstacles, you just miss that. Oh this curb, nonchalantly, going up the curb, going up the steps. Like with this wedding. ... So I was going to this bar, hang out for the reception. So we went to this local bar – can't remember what it was, some town of Leslie. And it wasn't accessible at all except for everybody walk up the stairs. You're thinking, 'Oh, how in the hell am I going to get up the steps?' Guy says "I'll pick you up." Say, "No, you don't need to pick me up." Then we find out another way to get in. It was these little things....*

Transportation problems

- *Right now, for sure, is the transportation. I'm working on getting back into the van, driving from the wheelchair, yeah, that's a big thing. That right now, for sure, is a...I've been trapped in the house pretty much, since I really threw out my shoulder and I did that when I was getting out of my car and up into the wheelchair, about a year ago or so. ... But yeah, transportation, the freedom of going wherever you want yourself, that's a big thing.*

Lack of money

- *Pain that I have now in different areas and bills and the snow, but otherwise I'm happy all the time usually.*

Area 7: Recommendations for Those with New Injuries

Participants were asked to use their experience to provide recommendations for others. We hoped that we accurately captured these wisdom and practical suggestions provided. Their responses reflected recommendations related to interactions with health care providers, actions to take (and avoid), things to understand or realize, and perspectives to adopt and suggested approaches to 1. Examples for each of these areas is below:

Interactions with Healthcare Providers

- Listen to the doctors. Or psychiatrists. Whatever available, take it. For your benefit ‘cause they know. That’s their job, they help people. That’s why they called specialists.
- I think that the – with me the doctors certainly played a role, a pretty big role, the doctors and the rehab people just in the sense of having hope that I would get to be – to whatever extent I would be functional. ... So I think that there’s a lot to the human body that is – the doctors know some of it, but they don’t know all of it. So a lot of it just is a function of getting up every day and doing what you’re supposed to do. ... I think you have to have hope and you have to, a little bit, be satisfied with what you can do and not the old story of looking at it half-full, not half empty.
- Yeah, stay informed about your own health and the things that are available to you. Don’t be ignorant about – especially in 2015, I mean with the internet. Find out if there is something out there that can help you do XY or Z. Anything that was something – When I was in the hospital there were these brainiacs in the basement of the hospital that, you know, they worked in the orthotics department and they would help you do anything you wanted to try to do.
- Experiment. Do things differently. Don’t get, you know, stuck in the same – You know, I’ve done it. We’ve done it. “You know, what the hell are we thinking? What were we thinking? Why didn’t we do this 20 years ago?” ... Yeah. This really stupid, simple things, yeah. Don’t be afraid to experiment and do things, you know. And don’t be afraid to experiment and do things differently than what the doctor told you to do too. Because if you do what your doctor tells you to do when you leave, you’re gonna be, you know, pretty limited. They’re conservative, you know. Don’t be so conservative. So, I guess that’s it.
- Number one, get your – get your seating proper, get the lightest chair you possibly can and adventure as much as possible.
- Advocate is a number one thing. Do that and like I say, the cushions are important, don’t – if you’re – I don’t care how active, they got low profile ro-hos, real cool things now you can hold the air side to side, it has a valve in the front. The ro-hos for your butt so you’re comfortable on the butt, ain’t going to be all sore and then learn how – the most ultra light chair you can get good with a wheelchair.

Actions to Take (as well as ones to avoid)

Stay active

- Get up and get out of bed every day and go do something. Get out in the fresh air. Very important. And not worry about things that you need help. Try to do things on your own. See other people, see what they do, things like that. Driving a car was a big thing for me. Once I started to drive a car again, I just felt independence like nothing.
- Don’t give up on yourself. Don’t give up on it. You give up on it, you’ve already shut down the process. So always keep that brain open up there that says, “Hey, these wires are going to go back together.” Just one of these days you’re going to wake up and go, “Boy that was bad dream I had there, wasn’t it?” But don’t give up on it.

Build networks / Make connections with people

- Man, man. I would hope for them that they do have a strong support system. If not they need good therapists, positive input, can-do attitude from anybody that’s around them. I know mine – every one that was around me had a positive attitude. And that’s a big part of it. If they can just realize that. I know when I first got there and I could do my hands – I could brush my hair, couldn’t do anything. I was like, “Oh my gosh, she’s making me try and brush my hair, my teeth.” And gradually I saw that her attitude – she showed me you can still do everything, but in a different way. It was just that positive input from, it seemed like, every angle that kept me going. And I was strong willed anyway – and determined. And I just rolled with that – just the positive instead of the negative. Again, I didn’t want to be like my cousin. He was hateful. It’s not over. I’m just in a chair. ... So, I guess, that

would be it. To surround their self with as many friends and family. And if they do need counseling, take them up on it. It is a lot to take in when you end up in a chair and I wonder too with other people that are worse off than me, I guess. I looked at them and thought, "It could be worse." So, I was just happy with – I was just glad that what I got was not like them, I guess. It sounds terrible to say it that way, but I'm glad my level of injury and that I regained a lot of the things that I did. I guess that's just the approach I took. It could have been worse. Make the best of what you got here.

Work to be as independent as you can

- So be positive, get over it. Let your friends help. Be as independent as you can. It's good to have all of the help in the beginning, but you need to do things on your own. Classic example of that is I tell all the younger kids on our hockey team, like most people are creatures of habit – and since this is for a university I'll just be as blunt as I can. So most people wipe their butt with the same hand. I always tell our kids on the team. I'm like, "Do things out of the ordinary. Use your other hands for a lot more other things than you normally do because if you're going to be an active paraplegic, without doubt, you're probably going to have an upper body surgery at some point and time." Don't do things the same way all the time. Do things a little bit differently. Lean to the other side. It will feel really weird. The first time I tried it, I fell right off the frigging toilet. Like okay, note to self, "Figure that one out just a little bit better." But there's always to do –whatever you want to do, you can do it. There's always ways to do it. Like I said, I've even skydived and that was a lot of fun.

Get involved / take advantage of services and organizations, like PVA

- Involved with, exactly. Absolutely is imperative, with the VA you've got to know what that's all about and get involved with whatever the Veterans of Foreign Wars or those organizations that become your sponsor within the VA and know what the VA – and be patient with it. It's a big system. You know you can't – it's not perfect. You've got to be patient with it. I think it's again one of those things where you get more out of it by being patient and being friendly and not being belligerent and expecting everybody to bend over backwards for you, then you get—

Find ways to connect with people

- Let me just think on that for a minute. I think just to realize that they are not alone hopefully. I mean I'm thinking that most people have some kind of a network and system. They should be looking for ways to reconnect and to realize that what they're feeling today isn't the way they're going to feel in the future. It may feel impossible now, but impossibilities become possible when you know what your attitude is; more of an "I can do" than an "I can't do." I don't know if that helps.

Connect with peers with SCI / disability

- If you can surround yourself with peer groups and surround yourself with positive people. Somebody told me one time at the Center for Independent Living, you need two of three. You need family, friends, or money. And if you have two of the three, you've got a shot. This is a guy who's been in a wheelchair for 35 years. I took that to heart, and I think that's so very, very true. So if somehow the people can surround themselves with positive energy, and positive reinforcement and constant – keep going. Push, push, push. If people can be encouraged. I don't know the mathematics, and the science of physical medicine and the way your recovery processes are most important, but people's mindset right out of the gate is excellence and doing your best. Somehow that can get communicated. How you tell that to somebody that was in a car accident that eats Cheetos and watches Oprah all day long, and how you get those people to be positive, I don't know the answer. But if there's some way people can find a silver lining out there, I just think that's so important.

Allow yourself to grieve but don't stop living

- So I would say those are the key takeaways for being happy. And it's not – and it's okay to be sad and 'why me?' for a while, but it's not okay to have that perpetuate. I couldn't tell you how long. I'm sure for each person that time period might differ, but it's something that shouldn't linger on for a really long time in my opinion. And I'm

no doctor, but I see a lot of people that get hurt and the ones that are the happiest, the ones that are the most successful, 100% bar none, are the ones that embrace their disability, have made the best out of it, are outgoing, friendly, and they've tried to minimize the effect that that had on their livelihood and the ability for them to have fun and continue to do the thing they enjoy and love.

Keep your body healthy

- *And even just like, if you don't want to walk again or if you don't think you're going to walk again, look into your health. So many people with spinal cord injuries are so unhealthy. You've got to work out still, exercise is still good for you. You don't want pressure sores, you don't want heart disease. There's just so many things, you've still got to work out, even if you don't want to work on walking, go to the gym, work out.*

Things to Understand / Realize

- I think the first thing that you need to realize is that there's life after this. I don't know what their circumstances are, or their level is. I'm very fortunate that I could do so many things. If you're a higher levels spinal cord injured person there's lots less things you can do. But with the technologies available today, there's a lot of things that are available with the computers and things like that, that will allow you to do. But just remember that there's, there is a life after spinal cord injury and that you can accomplish anything you want.
- There's a lot of people out there that will help you that you aren't even aware. Don't be afraid to ask for help. ... Some people think they can do it even though they can't do it. I can't pick up a little tiny screw and screw it into my glasses if I need to fix them. I need to have somebody do that for me. Don't be afraid to ask for help.
- If you are a newly spinal cord injury, don't let people tell you that the harder you work the better you're gonna be. Sometimes the injury level you're at, that's all you're going to get back as far as your physical abilities, no matter how hard you work. You just have to accept that and do the things that you can do, and not get too frustrated with the things that you cannot do.
- Get the most out of life that you can with what you can do. For the newly injured person, for me, if somebody told me that all you can do is this, and just accept it, I think I'd be a little bit more open minded to realize "yeah, this is it." You can strengthen the muscles you have. You just can't get back what's not going to come back. You have to accept that. I think some people get their hopes built up on "Oh I'll just work harder and harder and harder, and something will come back." It won't. There's always hope, they'd say; after a couple years of your injury, you realize your limitations, and that's all that's going to probably come back. You just have to accept it and move on with life. I think that's what I would... In fact that's what I was for Mary Free Bed a little bit, I was like a person where I could go in, and talk to newly injured people. Show them what's going on. Every injury is different. But basically, you still have a mindset. What's what. I guess that's what I would tell somebody.

Perspectives to adopt / suggested approaches to life

- *Back to what they can do, rather than what they can't do. If I was going to give you a one liner that's the way I'd give it to you.*

Take responsibility for your own life / be proactive

- *Yeah, I think that's just what independence is. Um, if—if you're going to be somewhat on your own, you have to take responsibility for what's—for what is, for the actions you—you choose to take. Um, I can't blame someone else, uh, for being independent. I'm the one who chose to be independent. Um—I didn't choose to have a spinal cord injury but I chose to be the one who did not stop drinking and that's what it led to. Um, yeah.*
- *Um—I would just say take responsibility for the, uh, for what you want to do from here on out, maybe. Um, I mean, from here on out, you have a new—you have a choice in everything you want to do. You can choose to be a nice person or you can choose to be the—the jerk that says, you know, "I told you to be here at this time. You're five minutes late!" [inaudible] Yeah, you—I mean, when you—if you're new to an injury, you can choose to have a different life, I feel. You can choose to have a positive one or you can choose to, um, push people away. That's*

not what I chose to do. I chose to be open with everything that's going on, open and accepting, um, others who are open and accepting in what they do as long as I was.

Stay positive

- *I'm just saying they need to keep a positive attitude. In this day and age, you can do anything with a spinal cord injury. It may not seem like that, you just have to learn how to do it differently.*

Don't let your disability define you

- *So I'd say support's the biggest thing, and just don't even quit. Just don't let the wheelchair define you. Just keep pushing it. People are totally able to live a normal life if not way more of a rewarding life being in a wheelchair than others that aren't. That's the way I view it.*

Determination / "push, push, push"

- *Push, push, push. If people can be encouraged. I don't know the mathematics, and the science of physical medicine and the way your recovery processes are most important, but people's mindset right out of the gate is excellence and doing your best. Somehow that can get communicated. How you tell that to somebody that was in a car accident that eats Cheetos and watches Oprah all day long, and how you get those people to be positive, I don't know the answer. But if there's some way people can find a silver lining out there, I just think that's so important.*

One day at a time

- *Right. So I just – I'm trying to think about myself. I don't know if I'm any more well-adjusted than the next person. In getting back to thinking about the survey, I don't know. Every day you have a choice and I think that's what comes back to you is you have a choice and you can be happy with your situation and you can move on, but I guess if you even talked to someone before and you had struggles and you weren't happy every day before the accident or wheelchair, whatever. So how do you expect that now that this is one more speed bump in the road or one more hurdle that it's any different? So I don't know. For me that's how I view every day. So one day at a time. I mean, yeah, that sucks but it's so accustomed to how I live, I don't even – that's not the part that I do a lot. More or less – like using this summer – I'm not thinking about, "Damn it, I'm in a wheelchair and I can't do this or that." I'm thinking more of, "Man, I'll get to see my daughter today." Those types of things. So I don't know, I wish there was like a perfect answer to help other people, but I don't think there is. I think it's case by case, situation by situation, individual by individual.*

Refocus on what you can do

- *Yeah. I guess a big point would be is to spend your time thinking about what you can do, instead of what you can't do. Because if you just sat there all day and thought about the things you used to do, you can't do now, that would destroy you.*
- *If you are a newly spinal cord injury, don't let people tell you that the harder you work the better you're gonna be. Sometimes the injury level you're at, that's all you're going to get back as far as your physical abilities, no matter how hard you work. You just have to accept that and do the things that you can do, and not get too frustrated with the things that you cannot do. Get the most out of life that you can with what you can do. For the newly injured person, for me, if somebody told me that all you can do is this, and just accept it, I think I'd be a little bit more open minded to realize "yeah, this is it." You can strengthen the muscles you have. You just can't get back what's not going to come back. You have to accept that. I think some people get their hopes built up on "Oh I'll just work harder and harder and harder, and something will come back." It won't. There's always hope, they'd say; after a couple years of your injury, you realize your limitations, and that's all that's going to probably come back. You just have to accept it and move on with life. I think that's what I would... In fact that's what I was*

for Mary Free Bed a little bit, I was like a person where I could go in, and talk to newly injured people. Show them what's going on. Every injury is different. But basically, you still have a mindset. What's what. I guess that's what I would tell somebody.

Area 8: Critical Resources, Programs, and Policies

Participants were asked about the resources, programs and policies that they felt were critical or that allowed them to do well after their SCI. While this came at the end of what – for some people at least – was a very long interview – the following responses were noted:

Information

- *But like I said, the instructions are on the internet and I highly recommend to anybody that needs to get social security, food stamps, any of these attendants, any of these assistance programs that you're going to have after disability – that you read the instructions. Because there's one golden rule that the state has – this is what burns most people – is they are not allowed to solicit services. They can't call you and tell you this program is available for you – they're not allowed. If they do that, they're in big trouble. They won't tell you that that's a policy, but that's a policy – they're not allowed to solicit services. That's like, the unwritten rule. And, here's the other part you're going to really love: a very high percentage of the people that work in the system there at the state don't know the rules themselves.*
- *It needs to be given when you're in the hospital. You need to give them resources. Whether they say you're going walk or not walk, whatever, they need to at least give you the option to look into it, to figure out, see what's going on.*
- *I just think definitely information, and I don't think...I guess, just the way they handle giving, telling you what the odds are and that kind of thing. I think they just need to be like, "We don't know," just, "We don't know," because they really don't. The books say this, you really just don't know, so they need to say that instead of saying...*

"Welcome to disability package"

- *Well, that's what I wanted with the CILs too, was to – that's the one thing, the entire time that I was there working on was trying to get – call it a welcome-to-disability package, whatever you want to call it, these are the things that you must do now because you're going to get burned if you don't. The whole Medicaid thing, they deny your stuff – those, they have to go back on retroactively, but that can be a lot of money and a lot of people got a lot of strain on them because they haven't received anything back saying that they're going to get it.*
- *Well, just everything. This is completely vague, but everything that I learned in the first three months. If that could have been consolidated into a nice neat pamphlet or handbook right after my accident that would have been a lot of help. But because every injury is different, they can prepare you in the general sense, but like I said, it's not even close to what you're going to encounter at home because right as you start thinking "Okay, you know, it's manageable," that's when you're going to get discharged from the hospital, and a house, an apartment, a condo, whatever you may be living in, isn't a hospital room. It's completely different. I know that when I came back there was no ramp into my house. So my dad and his friend had to put me into a manual chair to bump me up the steps, into the house. Then him and like 3 other guys had to carry my power chair in so I could get around the house. So, it's just, you have to understand that things are not even going to be close to the same. You can only try to move forward and take it day by day at first, because anything you try and plan is not going to work out until you start getting the hang of how things have changed.*

Information about Medicaid and social services

- *I said stay up on top of the rules and regulations for the food stamps and the Medicaid, that's a big, big thing.*

- *The biggest thing is Medicaid... Medicaid is there for that reason and they don't cut your pay first thing – first thing they do is cut your Medicaid benefits. So now, it's not, "I need this money to live comfortably," it's, "I have to have this money to survive." ...But like I said, the instructions are on the internet and I highly recommend to anybody that needs to get social security, food stamps, any of these attendants, any of these assistance programs that you're going to have after disability – that you read the instructions. Because there's one golden rule that the state has – this is what burns most people – is they are not allowed to solicit services. They can't call you and tell you this program is available for you – they're not allowed. If they do that, they're in big trouble. They won't tell you that that's a policy, but that's a policy – they're not allowed to solicit services. That's like, the unwritten rule. And, here's the other part you're going to really love: a very high percentage of the people that work in the system there at the state don't know the rules themselves.*

Information on weight management

- *So, and like, you know, I have body image issues now that I didn't have before and for years I, you know, could still eat anything I wanted and I was still fine but now I—I can't eat spaghetti and meatballs, try not to eat red meat, so my diet is, uh, pretty restricted for sure....I've always—I've always looked fit and now I don't look fit anymore. [Laughter] But I've cut down as much as I can...But you know, that's a big issue too is, um, I think right from the start, uh, in rehab they did not talk about weight gain as being something that's going to be inevitable and they shouldn't and I was eating full meals all through rehab and stuff. They should teach you to eat very small portions right from the very start and actually get used to that and know the importance of it. That also, I think, affects not only your weight, your body weight and then [inaudible] affects the pressure you're putting on your body.*

Programs and Policies

Personal care attendants and programs that support self-determination

- *Well, one of the biggest things I'm dealing with right now, like I said it's been 11 years since my injury; things are getting a little bit harder to do is getting someone to just come and help out with like daily things, like case in point the VA won't provide any home health aides unless it's medical related. I had Medicaid, which got cut about a month ago and they were providing someone six hours a week, which was perfect. ...Yeah. That's the biggest frustration for me right now is how I'm gonna be able to afford an aide to come help me with stuff as things get harder to do.*

ADA / accessibility enforcement

- *I was really surprised about how many places were not really very accessible, wheelchairs. Even some of the restrooms in the hospital and hotels and places like that that... So I think that there's still some things they can do as far as making things more accessible for wheelchairs.*
- *It's a lot – let me see – being disabled today is a million times easier than it was October of '89. I mean, you have hotels now that really have wheelchair accessible rooms and it's just the curb cuts and everything about it. The strides that have been made in the 25 or six years have been huge, just huge. People are way more willing to accept disabled people. You see more disabled people out doing their own thing. In the past you really didn't. So them people – all the disabled folks – being out in public has helped the public deal with them and I think it helps the disabled community as well dealing with all the able-bodied people. So that might help a little.*

Employment / Work supports

- *Like I said what pushed me was Michigan Rehab Services. Michigan Rehab Services, you have Michigan Works even. They help cater to people with disabilities as well. Goodwill Industries. ... I don't know if it is still there since I have been here, but Can-Do helped to promote and push people with disabilities as well to help get out*

and about. Your situation doesn't define you, you know; let us help you see that you can get beyond this. There are so many networks, 180 that helps people out for disability advocates. ... If they just - the resources of being able to know where to go and not only where to go, but have the want to go. Don't just sit and let your disability define you. See what you can do.

Support for PT / OT / recreational therapy

- *Therapy is the number one thing. ... Physical [therapy].*
- *I would say they should have more programs to help people adapt to the outdoors and different stuff - or whatever interest they have, you know. I guess I did have some of them programs, you know, but it was more dealing with sports and stuff like that, you know. I never had anybody like "Yeah you wanna get out in the woods, you know. We'll take ya out there, or something. You wanna get out there fishing?" I know it's not an easy thing. It wouldn't be an easy thing to implement, but I guess that'd be about it. Even just having a place people can get out to and explore and check out different place, besides just being stuck inside, because I think a lot of people are just stuck inside way too much of their lives.*

Peer mentoring

- *Policies. You know something that I never had was somebody that – what's it the – where somebody come talk to you in the spinal cord. They talk to you what to do. But sometimes when you talk to those people, they always been in the wheelchair for years or something like that. Take that away, take your sideguards away. Take your tippers away. You don't need that. You know and you talk like you've been in chair for years and years and you've spent a lot of chair for 30 days, you got a wheelchair. And you say no, I'm not – but have somebody that can relate to what you are right now. I think that's what the policy should have somebody, instead of have ... Yeah, mentor, yeah. Yeah, let's have a mentor that's been in a wheelchair for eons and gone through all the – even though they know what to go through, but have a mentor that actually been in a wheelchair for years and they say "Oh, okay. This is what you need to do. Don't worry about that, you'll learn that down the road."*

Rules about durable medical equipment and supplies

- *Well, I think the electric wheelchair option should be offered, encouraged for everybody with a spinal cord injury because in the long run, the complications, ... it's better to give them an electric wheelchair and encourage them, an electric wheelchair that tilts right away for pressure relief than he gets a regular wheelchair and then the person gets pressure sores and you have surgical complications, ambulance fees.*
- *There's one thing that I think it needs to be – it's stupid. If you use a catheter to urinate, I think the government or the state mandates that you get four per month. Like four. I pee seven or eight times a day. So I get 200 a month just because I fought this thing forever. But I think that's stupid. That rule or however all the healthcare companies – whoever guides that is 50 years ago. That's just ridiculous. So something needs to be done there.*

Inpatient rehabilitation ad continued outpatient therapy

- *You know everybody should have the ability – it's hard to say because of resources. But everybody should have the ability if you get hurt with a spinal cord injury to spend some time in a rehabilitation institute. It's not only for the physical part, but the mental part as well.*

Psychological and vocational counseling

- *Beneficial to people in chairs, like transitional counseling. Like from the time you're in the hospital – this is my social work background – but from the time you're in the hospital, maybe a social worker gets connected with you, like if they're a mental health therapist and then they just work with you maybe through a transitional period. Maybe this will be a policy, I don't know. But through maybe like a three or four-year transitional period, kind of get somebody from post-injury immediately to maybe where I am today. ... I think that it would be*

good to have a mental health therapist to kind of keep pushing them and helping them figure things out as they go. ... Yeah, regular contact with somebody who you can always depend on to provide you with some counseling or some help. It doesn't have to be that you're depressed at the time, but just to talk about stuff and to get things out on the table. ... Yeah, and I guess for help to transition into a career, maybe help a person to find his career that's going to interest them that they're able to do and then to get them – because I think the easiest thing to do after post-injury is to not think that you can make good money and get a real good job and stuff like that, and to keep them, I guess, from going – not that greeters at like Wal-Mart are bad, but just to keep them out of that mindset that they have to go to that job, that they can still achieve anything and maybe pursue education. I guess that's really [inaudible 0:17:30]. So that's one of the biggest things, I guess, is to help maybe get them to achieve their educational goal too.

Programs to support independent living and participation

- *Programs. Definitely want to look into all the organizations out there that are willing to help people with disabilities or spinal cord injuries or things like that. I was able to get involved with BVR here in Ohio and they were very helpful in getting my college paid for and things of that nature. I would say programs, you want to get involved with as many or just find as many as you can so that it's not such a burden on if you a vehicle or if you need to go to school or if need just adaptive equipment in your house. So then possibly get on a government program that will allow you to have an aide if you need her and things like that.*
- *The biggest thing is Medicaid... People on disability should not have co-pays on their Medicaid. People that don't have disabilities on social security, they could medicate with no spend-down. That's exactly, ass-backwards, how it should be. Now they got the waiver program, that's one of the best things they've done in a long time - is not starting a waiver program, because they started it quite a while ago. What became better about it is now they have self-determination on the waiver program. So, you can hire who you want instead of having to go through an agency.*

Participant Feedback Responses (see also Appendix E)

After reviewing and coding the transcripts, we wanted an opportunity to check our findings with those we had interviewed. We created a summary of findings that was set up to allow for the participants to easily give feedback to us. We mailed a hard copy with a highlighter and a business reply envelope to all of the living participants (one interviewee had passed away). We also offered an online version and the option to call in and give feedback. Nineteen of the 59 remaining interviewees provided feedback (ten by mail, nine online).

The report follows the same order of questions as the semi-structured interview. So it started with asking about lessons learned while growing up or from military service. The top three responses were work ethic (100%), responsibility (94%), and accountability (89%). These all involve taking charge and putting in the necessary work. This seems to be the basic building blocks of success.

The top cited feelings or thoughts immediately after injury were “confident that I will figure it out” (71%), “determination” (65%), and “uncertainty – ‘I didn’t know what to expect’” (65%).

The top response for factors that the interviewee associated with their adjustment process after injury was a need to move forward and get things done (81%). This connects with their responses regarding lessons learned and is a persistent theme in the later responses to the report.

When looking at behaviors associated with successful adjustment to their injury, including maintaining physical and emotional health and changing their environment, the most frequent responses were bowel and bladder management (94%), skin care (82%), and focusing on the positive and avoiding the negative (76%). One hundred percent of respondents cited adapting their house or car as a key to successful adjustment to SCI. An adapted home provides a safe haven that removes the struggle of just getting around for those with mobility impairments.

The things the interviewees cited as contributing the most to their happiness were doing work they enjoyed, being productive (82%), having a solid family foundation / how they were raised (82%). Seventy-one percent of interviewees also felt that spirituality / faith/ religion, a good disposition, keeping busy, and family (particularly children) contributed greatly to their happiness.

When asked about the best attitude to have for happiness after injury, 94% chose not dwelling on paralysis, accepting impairment, and moving on. This suggests an attitude of looking at “what I can do” and not “what I can’t do.”

The top recommendations for those with new injuries were to stay informed about their own health and the assistance available to them (63%); not giving up (65%); staying healthy (65%); realizing that there’s life after injury (82%); and accepting responsibility for their own life, health, and happiness (71%). The overarching theme of these responses was to take control of their own health.

The critical resources, programs, and policies chosen by the interviewees were somewhat dispersed across the options. We asked them to choose the one item from a list of information-based options and one from a list of programs and policies. Most of the options on the lists were marked as important. The most frequently noted important information to have for success after injury was information about their injury. The top program or policy was ADA and ADA enforcement (33%). Without accessible environments, daily tasks can become much more arduous and can sap independence from those with mobility impairments.

Key Research Accomplishments

While we expect to continue to extract and publish on the data that collected in both quantitative and qualitative stages of the projects, our findings suggest that many adults with SCI do adjust to and “flourish” after SCI, achieving happiness and a sense of purpose and meaning in their lives.

- Individuals with certain characteristics appear more likely to successfully adjust to SCI, reporting a sense of happiness and purpose and meaning in their lives; however, the direction of these relationships could not be ascertained from this study.
- In-depth examination of a stratified sample of adults who identified as being happy and feeling as if their life had meaning found that there may be certain factors related to social support, cognitive flexibility, and personality that may serve as protective factors or be related to resilience. These include low levels of neuroticism, strong social support systems, and at least average levels of cognitive flexibility.
- In addition, successful adjustment to SCI does not appear to be one thing or one approach; rather it seems that individuals may need, or at least benefit from having one or more of the following strengths or resources in order to deal with a spinal cord injury:
 - Attitude / Focus / Motivation
 - History of confidence and success
 - Skills of communication, problem-solving and adapting
 - Resources / Access to the right services at the right time
 - Support of family and friends (positive people)
- Three factors came repeatedly as being very important: a good attitude, health, and social connection and support. Health may not have been directly associated with flourishing, but our participants reported finding it harder to feel good if they were in pain or poor health.
- Active health management is critical, especially for those with higher level / more severe injuries.
- Finally, our interviews seemed to make clear that happiness and a sense of meaning in life were different, though often connected constructs. Some of our participants were happy; others felt that they made a difference and that their life had meaning. Many, but not all, expressed feeling both.

Reportable Outcomes

Manuscripts

- Duggan C, Wilson C, DiPonio L, Trumpower B, & Meade, MA (2016). Resilience and Happiness after Spinal Cord Injury: A Qualitative Study. *Topics in Spinal Cord Rehabilitation*, Spring 2016 pages 99-110.
- Perera M, Meade MA, & DiPonio, L. Use and Psychometric Properties of the Flourishing Scale among Adults with Spinal Cord Injury. *Rehabilitation Psychology*. (Manuscript submitted for publication.)
- Sol K, Drossel C, & Meade MA. Exploratory Study of Factors Associated with Flourishing in Adults Following Spinal Cord Injury. *Rehabilitation Psychology*. (Manuscript in preparation.)
- Meade MA, Trumpower B, & DiPonio, L. Characteristics of Adults who Flourish after Spinal Cord Injury. *Archives of Physical Medicine and Rehabilitation*. (Manuscript in preparation.)

Presentations and Workshops

- Harman I, Trumpower B, & Meade M (2015). Personality Factors Among Individuals with Spinal Cord Injury who are Flourishing. Undergraduate Research Opportunity Program (UROP) Poster Presentation, University of Michigan, Ann Arbor, MI, April 2015.
- Cadorin A, Trumpower B, Meade M, Duggan C, & DiPonio L (2015). Flourishing and Resilience Among Individuals with Spinal Cord Injury. Poster presented at 32nd Annual James W. Rae Scientific Day, Department of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, MI, May 15, 2015
- Trumpower B & Meade M (2015). Factors Associated with Flourishing & Successful Adjustment Among Individuals with Spinal Cord Injury (SCI). Research Presentation at the Academy of SCI Professionals, New Orleans, LA, September 2015.
- Meade M & Wilson C (2016). Resilience, Flourishing and Disability – Knowledge Translation with an Eye toward Innovation. Workshop presented at Rehabilitation Psychology 2016 Conference, Atlanta, GA, March 19, 2016.
- Sol K & Meade M (2016). Exploratory Study of Factors Contributing to Successful Adjustment Following SCI by Examining Cognitive Flexibility. Poster presented at Rehabilitation Psychology 2016 Conference, Atlanta, GA, March 20, 2016.
- Wilson C (2016). Translating Research Findings to Facilitate Successful Adjustment to Traumatic Spinal Cord Injury. Plenary Session at PVA Summit, Orlando, FL, August 31, 2015.
- Meade M & Wilson C (2016). Grand Rounds. James A. Haley Veterans' Hospital, Tampa, FL, December 8. 2016.
- Meade M (2017). Optimizing Health after Spinal Cord Injury: Identifying and Addressing Modifiable Factors. Keynote Address presented at the 2017 European Spinal Psychologists Association Meeting, Oxford, UK, April 27, 2017.
- Meade M (2017). Resilience, Flourishing, and Disability – Translating Research to Improve Clinical Practice, Programs, and Policy. Workshop presented at the 2017 European Spinal Psychologists Association Meeting, Oxford, UK, April 28, 2017.

Conclusion

There are a significant number of individuals living well with spinal cord injury. While it is possible that respondents to our survey do not necessarily reflect the entire population, their responses assert that living a good life and flourishing after SCI is possible. The interviews allowed for an in-depth exploration into the many pieces of resiliency after spinal cord injury. The next steps in the process are utilizing this information to inform education, policies, and procedures regarding the care of individuals with SCI.

Limitations: The sample size was small and may not be large enough to draw conclusions from the entire population of individuals with SCI. This study also does not explore the reasons why someone may not be flourishing – particularly the 42 survey respondents who scored in the bottom quartile (<25). The SNST results may have been compromised by the setting that it was administered in. The NEO-FFI-3 responses could have been skewed by some participants' desire to

answer in a socially desirable way. The tradeoff was necessary in order to ensure the participant understood the question and responded to all items.

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Appendices

Appendix A

- Survey on Adjustment and Quality of Life
- Semi-Structured Interview

Appendix B: Summary of Findings

Appendix C: Abstracts of Manuscripts (published, submitted, and in preparation)

- Duggan et al., Resilience and Happiness after SCI, 2016
- Perera et al., Flourishing Scale Factor Analysis (submitted for publication)
- Sol et al., Cognitive Flexibility (in preparation)
- Meade et al., Characteristics of Flourishing after SCI (in preparation)

Appendix D: Response Categories and Levels of Happiness (online appendix for Duggan et al., 2016)

Appendix E: Participant Feedback Responses

Appendix A: Assessment Measures

Survey on Adjustment and Quality of Life

Semi-Structured Interview

Survey Code

Survey on Adjustment and Quality of Life



Great Lakes SCI Collaborative



DMC
Rehabilitation Institute
of Michigan
always there.



THIS STUDY IS APPROVED BY THE ANN ARBOR DEPARTMENT OF VETERANS
AFFAIRS HEALTHCARE SYSTEM

Section I: General Information about your Spinal Cord Injury (SCI)

1. How old are you? _____ years old
2. How long have you had your spinal cord injury (SCI)? _____ (in years)
3. What is your highest level of SCI? *Check one only:*
¹ Between C1 and C4
→ Do you require a ventilator to breathe? ¹ Yes ² No
² Between C5 and C8 ³ Between T1 and T12
⁴ Between L1 and S3 ⁵ Don't know / not sure
4. Do you have any feeling below your level of injury? ¹ Yes ² No
5. Do you have any movement that is under your control below your level of injury?
¹ Yes ² No

Section II: Health, Income and Access to Care

6. Are you currently working at a job for which you receive pay?
¹ Yes ² No
↓
 - a. If yes, on average, how many hours per week do you work? _____
 - b. Do you receive any of the following from your job?
Check all that apply:
¹ Health benefits ³ Sick leave
² Paid vacation ⁴ Other: _____
7. What is your household income (combined income for all members of your household)
Check one only:
¹ Less than \$20,000 ⁴ \$40,000 to \$59,999
² \$20,000 to \$29,999 ⁵ \$60,000 or \$79,999
³ \$30,000 to \$39,999 ⁶ \$80,000 and over

8. Do you currently have health insurance?

¹ Yes  ² No

What kind of health insurance do you have? Check all that apply:

- | | |
|--|---|
| <input type="checkbox"/> ¹ Employer health plan | <input type="checkbox"/> ⁵ Veterans Administration |
| <input type="checkbox"/> ² Individual health insurance policy | <input type="checkbox"/> ⁶ Auto Insurance |
| <input type="checkbox"/> ³ Medicaid | <input type="checkbox"/> ⁷ Don't know / not sure |
| <input type="checkbox"/> ⁴ Medicare | <input type="checkbox"/> ⁸ Other: _____ |

9. In general, would you say that your health is:

¹ Poor ² Fair ³ Good ⁴ Very Good ⁵ Excellent

10. Has there been a time in the last 12 months when you needed medical care but were not able to get it?

¹ Yes  ² No

What was the primary reason that you did not receive the medical care you needed?

Check one only:

- | |
|--|
| <input type="checkbox"/> ¹ Transportation |
| <input type="checkbox"/> ² Unable to afford care |
| <input type="checkbox"/> ³ Unable to locate a health care provider |
| <input type="checkbox"/> ⁴ Unable to get an appointment in a timely fashion |
| <input type="checkbox"/> ⁵ Other: _____ |

11. Have you experienced any of the following problems within the past 12 months?

Check all that apply:

- | |
|--|
| <input type="checkbox"/> ¹ Pressure sores / skin breakdown |
| <input type="checkbox"/> ² Bladder problems, including frequent urinary tract infections (UTIs) or urinary accidents |
| <input type="checkbox"/> ³ Bowel problems, including chronic constipation or frequent bowel accidents |
| <input type="checkbox"/> ⁴ Problems managing blood pressure, including high blood pressure, low blood pressure and / or autonomic dysreflexia |
| <input type="checkbox"/> ⁵ Persistent, chronic pain |
| <input type="checkbox"/> ⁶ Emotional issues, including feelings of depression or anxiety |
| <input type="checkbox"/> ⁷ Respiratory issues, including pneumonia |
| <input type="checkbox"/> ⁸ Sleep-related breathing problems |
| <input type="checkbox"/> ⁹ Other: _____ |

Section III: Quality of Life

12. Generally speaking, how would you describe yourself as being happy?

- ¹ All the time ² Most of the Time ³ Some of the time
⁴ Very Infrequently ⁵ Not at All

13. When you compare yourselves with other people you know, would you say you are:

- ¹ Better Off ² Worse Off ³ About the same

14. Below are 8 statements with which you may agree or disagree. Using the 1 to 7 scale below, indicate your agreement with each item by checking the response for each statement.

	Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
I lead a purposeful and meaningful life.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁶	<input type="checkbox"/> ⁷
My social relationships are supportive and rewarding.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁶	<input type="checkbox"/> ⁷
I am engaged and interested in daily activities.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁶	<input type="checkbox"/> ⁷
I actively contribute to the happiness and well-being of others.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁶	<input type="checkbox"/> ⁷
I am competent and capable in the activities that are important to me.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁶	<input type="checkbox"/> ⁷
I am a good person and live a good life.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁶	<input type="checkbox"/> ⁷
I am optimistic about my future	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁶	<input type="checkbox"/> ⁷
People respect me.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁶	<input type="checkbox"/> ⁷

15. Is there anything else you would like to tell us about your resilience or ability to “bounce back” when you face a challenge? _____

16. Below are five statements with which you may agree or disagree. Using the 1 to 7 scale below, indicate your agreement with each item by checking the box that corresponds to your level of agreement. Please be open and honest in your responding.

	Strongly disagree	disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
a. In most ways my life is close to my ideal.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
b. The conditions of my life are excellent.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
c. I am satisfied with my life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
d. So far I have gotten the important things I want in life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7
e. If I could live my life over, I would change almost nothing	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7

Section IV: Demographic Information

17. Gender:

¹ Male

² Female

18. Marital Status: ¹ Single
⁴ Divorced ² Married/Partnered
⁵ Widowed ³ Separated

19. Have you ever served in the military?

¹ Yes  ² No

- a. Did you participate in combat? ¹ Yes ² No
- b. Do you receive Veterans Benefits? ¹ Yes ² No
- c. Do you receive care at a Veterans Affairs Health Facility? ¹ Yes ² No
- d. Are you service-connected for your SCI? ¹ Yes ² No

20. How would you describe the area where you live? Check one only:

¹ Urban ² Suburban ³ Small Town / Rural

21. What is your highest level of education? Check one only:

¹ Less than high school ⁴ Some college / Associates degree

² Some high school ⁵ Bachelor's degree

³ High school / GED ⁶ Graduate study or degree

Other: _____

22. What is your race / ethnicity? Check all that apply:

<input type="checkbox"/> ¹ White	<input type="checkbox"/> ⁵ Native Hawaiian / Other Pacific Islander
<input type="checkbox"/> ² Black / African-American	<input type="checkbox"/> ⁶ American Indian, Alaska Native
<input type="checkbox"/> ³ Asian	<input type="checkbox"/> ⁷ Hispanic / Latino
<input type="checkbox"/> ⁴ Middle-Eastern	<input type="checkbox"/> ⁸ Other: _____

If you checked more than one category, please indicate which group best represents your race: (write in race)

**UPON RETURN, THIS PAGE WILL BE SEPARATED
AND STORED APART FROM THE REST OF YOUR SURVEY RESPONSES**

23. If eligible, would you be willing to participate in an in-depth interview that will ask about you and the adjustment process that you went through after your SCI? This interview would last about 2 hours and take place at a location that would be convenient for you.

¹ Yes ² No ³ Maybe – tell me more

If you answered **yes** or **maybe**, please provide your name and a contact number or e-mail. This information will be recorded by researchers at the University of Michigan who may use it to contact you for the in-depth interview. Your contact information would only be used to contact you for this follow-up interview, which is identified as a separate study, and not used for any other purpose.

Name: _____

Phone number or e-mail: _____

**Thank you for completing this
survey**

**Please return it in the envelope
provided**

Semi-Structured Interview

Thank you once again for being part of this project. As you were told over the phone, through this project, we are looking to identify factors that are associated with people doing well after spinal cord injury so that we can try and create interventions, systems and programs that either facilitate or capitalize on those factors.

You were asked to be part of this part of the study because your responses to the Survey suggest that you are pretty satisfied with your life. Through the questions that follow, I am going to try and learn how you did it. In other words, I want to learn from your expertise.

Ready?

1) Tell me about yourself and how you got to this point in your life.

- a. Tell me a bit about yourself before your spinal cord injury. *What is your background? What were you doing? What factors shaped your life? Provide some details or specific examples.*
- b. Tell me about your SCI. *How did you get it [acquire your injury]? What happened immediately afterward? [or What was your life like immediately after your SCI?] How did you cope and adjust?*
- c. Tell me about your life now. *What are the important aspects of it?*

2) In thinking about what you said, can you tell me about some of the high points? What about the low points?

3) How did you get to where you are now? Were there any turning points in your life between your injury and now? [If YES, please tell me more about these turning points.]

Okay, you've already told me a lot. Now, though, I'm going to ask you to give more details so that I can better understand the various aspects of your life including people, decisions, and behaviors that may have influenced your path.

4) Tell me more about your background. *Describe some of the key events or people that may have shaped your choices and actions. Probe about:*

- *Family and support system*
- *Experience in the military (what you learned); what were the key messages or expectations?*
- *Culture*
- *Community*
- *Environment / socioeconomic background*
- *Interactions with the healthcare system*
- *Spirituality and religion*

5) Now I want to find out more about how you thought about things immediately after your spinal cord injury and how you think about things now.

- a. Describe your general outlook on life. *Do you expect it to be fair? Good? If YES, Have you always thought this way? If NO: Tell me more about your general outlook on life and whether or not it has changed over time.*
- b. What were your thoughts immediately after you became injured? *About life? About yourself? Your injury? Disability / SCI? Other?*
- c. Did those thoughts change over time? *If YES, please tell me how your thoughts changed.*
- d. What are your thoughts about life now? And about the future?
- e. In thinking back about your life after SCI were there times when you recall making a decision (or a conscious choice) about how to approach or address issues or novel situations that come up in your day-to-day life. *If YES, please describe in some detail.*

6) Okay, now that you have told me how that you thought about things, I want to find out more about what you actually did. Were there specific actions which were consciously performed to advance priorities and promote health and quality of life?

What did you do to manage your health? Prevent secondary conditions? Optimize functioning?

How did you deal with your family and others? Communicating and setting boundaries?

Participants will be encouraged to talk about specific behaviors and actions they engaged in to manage their health, regain a sense of independence and purpose, and connect to other people.

7) In thinking about everything that you have said during this interview, what things do you feel most contribute to your happiness or satisfaction with life? What things do you feel most DETRACT from happiness and satisfaction with life?

8) Finally, what do you think is most important for those with new spinal cord injuries to be able to adjust and be successful? *What information should they know? What perspectives should they adopt? What actions should they take? What programs or policies would be most beneficial to them?*

Appendix B: Summary of Findings

Happiness, Resilience, and Quality of Life among Individuals with Spinal Cord Injury

Summary of Findings
February 2017



University of Michigan Institutional Review Board # HUM 00064638

February 2017

Hello,

We would like to thank you once again for participating in our research interview on the quality of life among individuals with spinal cord injury (SCI). Your time and willingness to share your experiences have allowed us to gain insight into what bouncing back from SCI really means.

We are contacting you now to ask for your feedback about our findings. Enclosed you will find a yellow highlighter marker, a stamped return envelope, and two versions of our report:

- A Summary of Findings (a shorter version of the Report of Participant Responses)
- A Report of Participant Responses

We hope you will review the Summary of Findings and, beginning on page 6, use the highlighter pen to provide feedback regarding several topics before sending the report back to us by March 31, 2017.

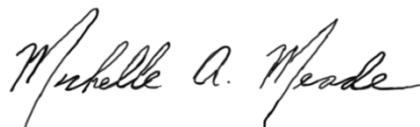
The Report of Participant Responses is yours to keep, and to use as a reference for more information about each of the areas included in the Summary of Findings.

You also have the option to provide feedback online if you prefer. We have sent these two reports, plus instructions for providing online feedback, in an email message, but we don't have email addresses for everyone. If you did not receive the email version, please send your email address to UM-PMR-CTHI@med.umich.edu

Hearing from you is essential for our final report. We will incorporate your feedback into that report, which will be shared with the Department of Defense as well as the other groups that participated in this research (the Rehabilitation Institute of Michigan and the Michigan Chapter of the Paralyzed Veterans of America).

Thank you again for your contribution to this important research.

Sincerely,



Michelle Meade, Ph.D.
Associate Professor, Project Director



Brad Trumpower, M.S.
Study Coordinator

Happiness, Resilience, and Quality of Life Among Individuals with Spinal Cord Injury

Purpose of the Summary of Findings

1. To provide you – the participants – with information about study findings and results.
2. To clarify issues raised by both the study and its findings and to ask additional questions.
3. To get feedback from you to inform our interpretation of results and conclusions.

Study Overview

While there is ample evidence that individuals with spinal cord injury (SCI) can experience a high quality of life, there is little understanding about how this happens. Research on adjustment after SCI has generally focused on identifying fixed characteristics such as race, resources, or personality that serve as risk factors or supports, as opposed to looking for factors that can be changed or modified. However, previous studies suggest that key events, experiences, and ways of thinking (cognitions) shape future decisions, behaviors, and outcomes for individuals with SCI.

Specific Goals

The objective of this investigation is to examine how what people think, the decisions they make, and the actions they take after SCI are associated with good adjustment and positive outcomes among individuals from both military and nonmilitary backgrounds. In particular, we proposed the following goals for the project:

Goal 1: Gather details about the cognitions, decisions, and behaviors of individuals with SCI after injury that may have been instrumental in promoting positive outcomes.

Goal 2: Analyze and compare data obtained from military and nonmilitary participants to determine similarities and differences, if any, in decisions, cognitions, and behaviors and their relationships to more global psychosocial and environmental factors and characteristics.

Goal 3: Interpret, summarize, and share project results with various stakeholders to facilitate the development of new assessments, interventions, and programs that enhance successful adjustment among individuals with new SCI.

Impact

It is critical to identify the cognitions, decisions, and behaviors that are associated with successful adjustment among individuals with SCI in order to better inform treatment and improve outcomes for others. Information from this study will be used to develop interventions to support the adjustment of military personnel with SCI, including both direct patient programs and professional training modules, which can also be adapted for use by individuals not in the military.

Study Design

This study is the second phase of a larger project funded by the Department of Defense entitled *Cognitions, Decisions, and Behaviors Related to Successful Adjustment among Individuals with SCI: A Qualitative Examination of Military and Nonmilitary Personnel*. (The first phase consisted of a survey completed by over 400 individuals.) The primary goal of this phase was to interview individuals with SCI from both military and nonmilitary backgrounds who experienced successful adjustment to SCI, defined as good emotional health, happiness, and participation in family or community activities.

Recruitment Methods

Potential interview participants were those who responded to the Phase 1 survey and provided their names and contact information. From the survey, information on military background, resources (household income and insurance coverage), and time since injury, as well as responses indicating successful or unsuccessful adjustment, was used to recruit a stratified (balanced) sample.

We used the Flourishing Scale as part of the survey in Phase 1 of the project to identify individuals who seemed to be doing well. This measure looks at how people see themselves in important areas such as relationships, self-esteem, purpose, and optimism. Individuals who scored in the top 50% of participants were categorized as “successful” and were invited to participate in Phase 2 of the study.

Sample Characteristics

We completed a total of 60 interviews (29 military, 31 nonmilitary). Of those who were in the military, 10 were combat veterans, 19 receive VA benefits, and 22 receive care at a VA healthcare facility. Nine of the 29 injuries were service connected.

Ages ranged from 20 to 90 (the average age was 50.5). Only 9 of the interviewees were female, which is in line with the nationwide male-female split for SCI. Fifty-one of the participants were White, 4 were Black, 1 was Native Hawaiian, and 4 identified themselves as multiracial. Incomes ranged from less than \$20,000 per year to \$80,000 and over.

Twenty-seven were married or partnered, 18 were single, 13 were divorced, and 2 were widowed. The majority of participants live in suburban (22) or rural (28) areas; the other 10 live in urban areas. Everyone had at least a high school diploma or GED; most individuals (47) had at least some college, with 24 having a Bachelor's degree or higher. Most (40) were not employed.

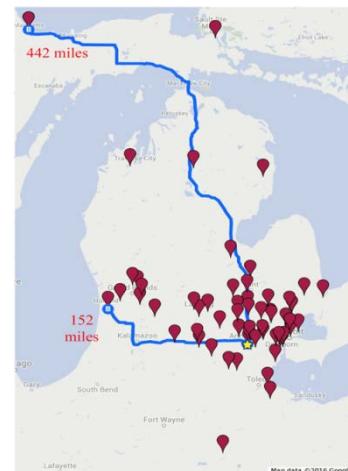
There was a range of injuries from between high cervical to S3, but the most frequent injury level (25) was between T1 and T12. Thirty-one had movement below their level injury and 37 had feeling below the level of injury. All but one person reported having health insurance. Medicare (31), employer health plan (21), and VA (17) were the most common sources of insurance. Most (48) rated their health as good, very good, or excellent.

Interviews

Participants were interviewed in a comfortable location (primarily in their homes), with interviews lasting between 30 minutes to 3½ hours. A map of participants' locations is provided here.

The interview focused on the following questions:

- 1) Tell me about yourself and how you got to this point in your life.
- 2) In thinking about what you said, can you tell me about some of the high points?
What about the low points?



- 3) How did you get to where you are now?
- 4) Tell me more about your background.
- 5) Now I want to find out more about how you thought about things immediately after your spinal cord injury and how you think about things now.
- 6) Were there specific actions which were consciously performed to advance priorities and promote health and quality of life?
- 7) In thinking about everything you have said during this interview, what things do you feel contribute most to your happiness or satisfaction with life?
- 8) Finally, what do you think is most important for those with new spinal cord injuries to be able to adjust and be successful?

Background of Participants

In addition to the demographic information collected in the survey, participants also told us more about themselves during the interview. From this, we discovered that individuals who were identified as flourishing after SCI did not come from one specific type of background. They came from diverse areas of the country. Some were born in Michigan while others were from other regions of the country.

Some participants told us that they had moved around a number of times as a child. It may be that in doing so, they developed the ability to adapt to new situations – a skill that may have helped after their SCI.

For the most part, our participants grew up in rural or suburban areas. The areas where they grew up may have impacted their relationships to other people.

While many of the participants appear to have grown up in supportive two-parent families, this was not universally the case. However, most of the individuals indicated that they felt safe and supported even if their parents were divorced. Relationships with siblings were also generally characterized as good. Many participants felt as if they had grown up with strong family ties and a strong support system. Even those who discussed having experienced more challenges growing up were able to identify positive influences on their lives.

Socioeconomic Background

Being able to adjust to SCI did not appear to be associated with one particular socioeconomic background. Some participants described growing up poor, while others were in the middle or upper classes. Even those with less income and fewer resources, though, described having “enough” and feeling as if their actions made a difference, both in their lives as well as in the lives of others.

Education

All of the participants graduated from high school or earned a GED. Some had attended college to varying degrees. Many of those who stopped after high school stated that they had done so not because of a lack of intelligence, but because they were not interested in school and did not apply themselves.

Personality

Many participants described themselves as outgoing, active, and social. Others described being entrepreneurial. Some participants described themselves as athletes while growing up and appeared to associate benefits from that type of activity and role. Others just described themselves as active, particularly in participating in outdoor activities. Only a few described themselves as introverted.

Religious Upbringing

Religion played different roles for different people in this study. Some individuals were raised in religious families, while others were not.

Cognitive Flexibility

Participants in this study were given the Stroop test, a measure of mental sharpness and flexibility. They were first presented with the Color Task to assess reading accuracy. The second task, the Color-Word Task was used to show how quickly and accurately they were able to take in the information they saw and give us the information we were looking for, which was the color of the word. The higher the score, the better. Overall, the scores were pretty similar to what is found in the general population. Our findings suggest that individuals who have been successful with adjusting to their SCI generally have a good level of cognitive flexibility, which allows them to problem-solve and deal with new situations and environments.

Social Support

Participants' responses on a standardized measure of social support (the Interpersonal Support Evaluation List, or ISEL-12) appear to support the importance of people in their lives. The ISEL-12 measures the extent to which respondents feel they have people to socialize with or provide them with emotional or practical support. The higher the score, the more social support that person believes he or she has. Our participants' scores were only slightly higher than the normative sample, which is consistent with the operational definition we used for success after SCI (that is, to flourish). Moreover, it seems to suggest that most participants felt they had people they could count on when they really needed it.

Background Values and Habits

Participants in our study mentioned specific values, habits, and lessons they learned while growing up that they felt were important in making them the person they were. For some, these values were learned from their families; for others, it was the military that instilled these values.

Please use your highlighter on each word below that applies to you as a lesson learned while growing up or a lesson from your military service.

- Accountability
- Ability to adapt
- Attitudes
- Communication
- Confidence
- Cooperation
- Discipline
- Goal-setting
- Improvise
- Independence
- Integrity
- Leadership
- Listening
- Organization
- Patience
- Perseverance
- Relationships (and their importance)
- Respect
- Responsibility
- Survival
- Work ethic

What were other “lessons learned” while you were growing up or in the military that should be added to this list?

Feelings and Thoughts Immediately after SCI

We were interested in what participants felt and thought immediately after their spinal cord injury. Since it is sometimes difficult to accurately recall that type of information – especially given the range of years that has passed – the information below can probably be best thought of as current recollections about thoughts (cognitions) and feelings (emotions) after the SCI.

Please use your highlighter to mark feelings or thoughts you experienced immediately after your injury.

- Depression / sadness
- Suicidal
- Anger
- Worry / anxiety
- Uncertainty – “I didn’t know what to expect”
- Helplessness
- Unphased by the injury
- Broken / broken down
- Determined / determination
- Discouragement
- Feeling bad / feeling sorry for family members / feeling like a burden
- Acceptance
- Negative
- Stunned
- Caught up in what I cannot do
- Unsure / unfocused
- Worried about others
- Confident that I will figure it out
- Focused on recovery / walking
- Detached
- Positive

What were other feelings or thoughts that you recall from the time immediately following your injury?

Path to Current Life and Sense of Flourishing

Participants described various pathways to their current sense of satisfaction with life. While some individuals talked about a gradual process, others mentioned specific realizations or events that served as turning points for them. In addition, for some participants, family members were key in providing the support and motivation to continue to move forward.

Please use your highlighter to select the path below that is most similar to your experience.

- Steady / no real changes
- Gradual process
- A series of choices
- A process of hard work and determination

Please use your highlighter on any of the turning points listed below that were important in your experience.

- Recognition of my ability and strengths
- Changes in perspectives and approaches
- Sports
- Independence / moving out on my own
- Employment
- Desire to prove others wrong
- Increased social comfort
- Wanting to make a difference for others / impact
- Spirituality
- Motivated by others / importance of family and friends
- Motivated by opportunities

Please use your highlighter on any factor(s) in the list below that you associate with your adjustment process after your SCI.

- Need to learn patience
- Finding a sense of acceptance
- Learning what was possible
- Find a sense of purpose and meaning
- Disconnecting from people who don't understand
- Taking responsibility
- Allow yourself to grieve
- Reconnect with who you are and pre-injury identity
- Avoid negative thoughts
- Need to move forward and get things done

What were other paths, turning points, or factors that contributed to your adjustment to life after your SCI?

High points

Most of our participants reported experiencing full and meaningful lives. The high points they described reflected the importance they placed on family, relationships, activity, recognition, and making a difference in people's lives. This was so well articulated in the following statement:

High points? ...Faith, family, friends. ...The ability to do things, the ability to do work I love. I love having my own little business. I love being involved in my kids' lives. I love coaching, I love being able to contribute. ...And love for the memories I have of great parents and siblings.

Families, including spouses, children, and grandchildren, were mentioned most frequently as being the best part of life after SCI. Friendships and romantic relationships were also important. Many participants mentioned sports and recreational activities as high points in their lives. These included competitive sports as well as activities that allowed them to just relax and enjoy life.

For some participants, continuing or completing their education brought with it the opportunity to connect with people as well a sense of self-worth and accomplishment. One high point that was both explicitly stated as well as implied by many was how our participants valued making a positive impact on others. Other notable highlights included returning to work and career, traveling, and building a home.

Do any of these high points reflect your experience? Yes No

What did we miss, or what would you like to add?

Low Points

Participants in this study discussed the various low points they had experienced since their SCI. While some were directly related to their injury, others appeared related to losses, hassles, and frustrations that are common in the general population.

Although the spinal cord injury itself was mentioned as a low point by some, not all (or even the majority) of participants cited their SCI as a low point. Other participants articulated specific factors associated with their SCI that they struggled with.

Low points included:

- *Not knowing what to do or expect*
- *Decreased functioning / aging with SCI*
- *Hospitalization / illness / surgeries*
- *Healthcare providers*
- *Feeling isolated*
- *Red tape*
- *Frustrations associated with impaired physical function*
- *Frustrations associated with needing the assistance of others*
- *Disability-related employment issues*
- *Missed opportunities*
- *Lack of accessibility*

Finally, for some participants, low points were factors that did not appear to be directly associated with the SCI – things like problem bosses, bad marriages, financial hardships, and the poor health or death of family members.

Do any of these low points reflect your experience? Yes No

What did we miss, or what would you like to add?

Why do you think most participants did not list the injury itself as a low point?

Current Thoughts about Life / Attitude / Outlook

While we selected participants based on a general sense of well-being and feeling as if they lived a purposeful life, we also felt that it was important to learn a little more about that specific attitude or outlook. The responses below summarize what we heard.

Please use your highlighter on any of the thoughts or attitudes in this list that apply to you today.

- Positive / good / life is good
- Desire for a family and a good life – do what you need to do to get there
- SCI as a speed bump
- Feel thankful, lucky, and grateful
- Optimistic, hopeful
- Things are the same – may take a little longer
- Realistic / day by day
- Pessimistic / cynical
- Life is not fair but you deal with it
- If you want something, work for it and earn it
- Don't take anything for granted
- Everyone has their struggles
- Happy / enjoy life
- Taking it as it goes
- Experience regrets but not letting them consume me
- Life is life

What other thoughts or attitudes apply to you today?

Behaviors Associated with Successful Adjustment to SCI

In general, participants identified three overlapping categories of behaviors that seemed to be associated with being able to do well or flourish after SCI. These included behaviors associated with maintaining physical health, behaviors associated with maintaining emotional health, and behaviors associated with changing the environment.

Please use your highlighter on any items in this table that you associate with doing well after SCI.

Working to Maintain Physical Health	Working to Maintain Emotional Health	Changing the Environment
<i>Being proactive</i>	<i>Learning how (and who) to ask for help</i>	<i>Adapting house, car</i>
<i>Listening to medical advice</i>	<i>Problem-solving / figuring out what can be adapted and do it</i>	<i>Creating tools</i>
<i>Develop a routine or structure</i>	<i>Setting goals</i>	<i>Do-it-yourself projects</i>
<i>Exercise</i>	<i>Relationships / social networks</i>	
<i>Diet</i>	<i>Talk to / work with a mental health professional</i>	
<i>Skin care – monitoring and prevention</i>	<i>Support groups</i>	
<i>Bowel and bladder management</i>	<i>Meditate</i>	
<i>Pain management</i>	<i>Be aware of / in touch with your feelings</i>	
<i>Fatigue management</i>	<i>Prayer</i>	
<i>Range of motion</i>	<i>Return to work / school</i>	
<i>Weight management</i>	<i>Adaptive sports</i>	
<i>Medication management</i>	<i>Keep your brain working</i>	
<i>Blood pressure management</i>	<i>Focus on the positive / avoid the negative</i>	

What other behaviors (if any) do you associate with your successful adjustment to SCI?

Things that Contribute to Feelings of Happiness

When asked about things that contributed to feelings of happiness, most of our participants mentioned people in some way – people in general, family members, or friends. Activities and other personal factors also play an important role. Finally, the attitude or approach to life that people adopted was mentioned by many respondents.

Please use your highlighter on anything in the four groups below that contributes to your feelings of happiness.

People

- *People in general*
- *Family, particularly children, including adult children and grandchildren*
- *Networks of friends*
- *A good support system*
- *Siblings who are willing to help*
- *Others with SCI*

Activities

- *Keeping busy*
- *Volunteering / helping others*
- *Wheelchair sports*
- *Doing what you enjoy*
- *Returning to pre-injury activities such as hunting and fishing*
- *Being able to get up and around and do most things that need to be done*
- *Work you enjoy / employment / being productive*

(continued on the next page)

Continue highlighting the factors below that contribute to your feelings of happiness.

Other Personal Factors

- *Good disposition / personality*
- *Pets*
- *"My land"*
- *Spirituality / faith / religion*
- *Family foundation / how I was raised / parents*
- *Financial resources*

Approach to Life / Attitude

- *Quest to be as independent as possible*
- *Accomplishing things / getting things done*
- *Taking on challenges and being able to overcome / pushing yourself*

(Approach to Life / Attitude cont'd)

- *Sense of purpose*
- *Having goals and something to work toward*
- *Recognize the impact you can have on your own life and its outcome, even with SCI*
- *Not dwelling on paralysis / accepting impairment and moving on*
- *Positive attitude*
- *The drive to prove people wrong, to work, to contribute*
- *Determination / persistence*
- *You are responsible for your own happiness*

What else contributes to your feelings of happiness?

Things that Detract from Your Feelings of Satisfaction or Happiness

Possibly because of the way we selected participants for this study, most people were not focused on the negative things in life and did not dwell on what detracted from their happiness. Responses tended to fall into three general categories: (a) internal factors associated with their impairment and health, including psychological factors; (b) interpersonal factors, such as the attitudes of others; and (c) environmental factors, including policies and physical accessibility.

Please use your highlighter on any factors in list below that take away from your feelings of satisfaction or happiness.

Internal factors associated with health and impairment

- *Pain*
- *Self-image*
- *Limitations on mobility*
- *Poor health*
- *Increasing functional limitations – things are getting harder*
- *Frustration with the lack of independence / dependence on everyone*
- *Nuisance of needing to carry around supplies*
- *Neurogenic bowel and bladder*
- *Erectile dysfunction*
- *Negative thoughts and tendencies*
- *Relatively minor nuisances and frustrations associated with physical impairment*

Interpersonal Factors

- *Divorce*
- *Lack of partner / relationship*
- *Concerns about children*
- *Suffering of others*
- *Perceptions of the public / media*
- *Inconsiderate or negative people*

Environmental factors, including policies and physical accessibility

- *Insurance companies*
- *Lack of accessibility*
- *Transportation problems*
- *Lack of money*

What else (if anything) takes away from your feelings of happiness?

Recommendations for Those with New Injuries

Participants were asked to use their experience to provide recommendations for others. We hope that we have accurately captured the wisdom and practical suggestions that were provided. If not, please add to these.

Please use your highlighter to mark the one MOST important recommendation in each section below.

Interactions with healthcare providers

- Listen to the doctors.
- Have hope.
- Stay informed about your own health and the things that are available to you.
- Experiment. Do things differently.
- Get your seating proper, get the lightest chair you possibly can, and adventure as much as possible.
- Advocate is a number one thing.

(continued on the next page)

Continue highlighting the one *MOST* important recommendation in each section below.

Actions to take (as well as ones to avoid)

- *Stay active.*
- *Don't give up on yourself.*
- *Build networks / make connections with people.*
- *Work to be as independent as you can.*
- *Get involved / take advantage of services and organizations, like PVA.*
- *Find ways to connect with people.*
- *Connect with peers with SCI / disability.*
- *Allow yourself to grieve but don't stop living.*
- *Keep your body healthy.*

Things to understand or realize

- *Realize that there's life after this.*
- *There are a lot of people out there that will help you that you aren't even aware of. Don't be afraid to ask for help.*
- *Don't let people tell you that the harder you work the better you're going to be. Sometimes the injury level you're at, that's all you're going to get back as far as your physical abilities, no matter how hard you work.*
- *Get the most out of life that you can with what you can do.*

Perspectives to adopt / suggested approaches to life

- *Be proactive – "push, push, push."*
- *Stay positive.*
- *Don't let your disability define you.*
- *Accept responsibility for your own life / health/ happiness.*
- *Be willing to tailor and adapt things.*
- *One day at a time.*
- *Focus on what you can do, rather than what you can't do.*

What other recommendations would you like to add at this time?

Critical Resources, Programs, and Policies

Participants were asked about the resources, programs, and policies that they felt were important, or that allowed them to do well after their SCI. While this came at the end of what was, for some, a very long interview, the following responses were noted:

Please use your highlighter to identify the one *MOST* important issue in each section.

Information

- *About your injury*
- *About social services, benefits, attendants, insurance, federal programs, etc.*
- *About what happens next*
- *Given during inpatient but also available later on*

Programs and policies

- *Personal care attendants*
- *Programs that support self-determination*
- *ADA / accessibility enforcement*
- *Employment / work supports*
- *Support for PT / OT / recreation therapy*
- *Peer mentoring*
- *Rules about durable medical equipment and supplies*
- *Inpatient rehabilitation and continued outpatient therapy*
- *Psychological and vocational counseling*
- *Programs to support independent living and participation*

What other resources, programs, and policies are needed?

Putting It All Together

Successful adjustment to SCI does not appear to be one thing or one approach; rather it seems that individuals may need, or at least benefit from, having one or more of the following strengths or resources in order to deal with a spinal cord injury:

- Attitude / focus / motivation
- History of confidence and success
- Skills of communication, problem-solving, and adapting
- Resources / access to the right services at the right time
- Support of family and friends (positive people)

Three factors came up repeatedly as being very important: a good attitude, health, and social connection and support. Health may not have been directly associated with flourishing, but our participants reported finding it harder to feel good if they were in pain or poor health. Having a support network and people you can count on in your life was also critical.

Finally, our interviews seemed to make clear that happiness and a sense of meaning in life are different though often connected constructs. Some of our participants were happy; others felt that they made a difference and that their life had meaning. Many, but not all, expressed feelings about both.

Please use the space below to provide any additional comments or suggestions you have about this Summary of Findings. We would like to find out more about what you think of it. For instance, did any of our findings surprise you? Did any particular part of the summary stand out to you?

After you have finished highlighting and adding comments to this report, please use the enclosed stamped envelope to return your feedback to us by March 31, 2017. (You can keep the highlighter.)

If you do not have the envelope, here is our address:

***Brad Trumpower, Study Coordinator
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If you have any questions about this report, please feel free to email us at:

UM-PMR-CTHI@med.umich.edu or call: (734) 615-6720.

Thank you for your participation in our research.

Appendix C: Publications

Duggan et al., Resilience and Happiness after SCI (Abstract)
Published in *Topics in Spinal Cord Injury Rehabilitation*, Spring 2016

Perera et al., Flourishing Scale Factor Analysis (Abstract)

Sol et al., Cognitive Flexibility (Abstract)

Meade et al., Flourishing after SCI (Abstract)

Resilience and Happiness after Spinal Cord Injury: A Qualitative Study

Published in *Topics in Spinal Cord Injury Rehabilitation* 2016;22(2):99–110

by

Colette Duggan, PhD, Catherine Wilson, PsyD, Lisa DiPonio, MD,
Brad Trumpower, MS, and Michelle A. Meade, PhD

Abstract

Objective: The purpose of this study was to identify factors associated with resilience among individuals with spinal cord injury (SCI).

Methods: Qualitative analyses were conducted of the written comments that were completed as part of a cross-sectional survey of individuals with SCI living in the community. More than 1,800 mail surveys were distributed to individuals identified as having a traumatic SCI through the records and/or membership lists of 4 organizations. Four hundred and seventy-five individuals completed and returned the survey, with approximately half (48.6%; $n = 231$) of respondents answering the open-ended question “Is there anything else you would like to tell us about your resilience or ability to ‘bounce back’ when you face a challenge?”

Results: Analyses of these responses identified both specific resources and cognitive perspectives that are associated with perceived happiness. Responses fell within 8 general categories: resilience, general outlook on life, social support and social relationships, religion or faith in a higher power, mood, physical health and functioning (including pain), social comparisons, and resources. Nuanced themes within these categories were identified and were generally concordant with self-reported level of happiness.

Conclusion: A majority of respondents with SCI identified themselves as happy and explained their adjustment and resilience as related to personality, good social support, and a spiritual connection. In contrast, pain and physical challenges appeared to be associated with limited ability to bounce back.

Key words: *adjustment, happiness, resilience, spinal cord injury*

Use and Psychometric Properties of the Flourishing Scale among Adults with Spinal Cord Injury

Manuscript submitted to *Rehabilitation Counseling*

Marisa J. Perera, MS, Michelle A. Meade, PhD, and Lisa DiPonio, MD

Abstract

Purpose/Objective: Despite increased interest in the topic of resilience in rehabilitation, there has been no psychometric investigation of the Flourishing Scale (FS; Diener et al., 2010) in a sample of adults with spinal cord injury (SCI). The present study examined the reliability, convergent validity, and factor structure of the FS.

Research Method/Design: Data for this project were extracted from a larger study on happiness and quality of life after SCI. For this study, information was collected using a cross-sectional mail survey design of adults with SCI. More than 1800 mail surveys were distributed and 642 were returned; however, only 472 of these were valid. Respondents were primarily male, White, and had either cervical or thoracic injuries. Confirmatory factor analysis (CFA) was used to examine the unidimensional structure of the FS.

Results: Descriptive statistics were not considerably different from prior studied samples. CFA supported a one-factor structure with all eight FS items loading on a single flourishing factor. The scale demonstrated good internal consistency. Convergent validity analysis indicated the FS factor was positively related to Satisfaction with Life Scale scores (Diener, Emmons, Larsen, & Griffin, 1985; $r = .674$, $p <.001$) and self-reported happiness ($r = .639$, $p <.001$).

Conclusions/Implications: The total computed FS score appears to be a valid assessment measure for clinical and research use with SCI patients in the United States.

Key Words: Spinal Cord Injury; Flourishing Scale; Rehabilitation Psychology; Psychometric; Factor Structure.

Exploratory Study of Factors Associated with Flourishing in Adults Following Spinal Cord Injury

Manuscript in preparation

Ketlyne Sol, PhD, Claudia Drossel, PhD, and Michelle A. Meade, PhD

Abstract

Objective: “Flourishing” is one term used to describe when an individual is able to adjust well in the face of adversity, such as experiencing a spinal cord injury (SCI). Several factors contribute to adjustment (and subsequent flourishing), including personality, cognitive, and social characteristics. All of these aspects have been found to contribute to successful outcomes in chronic disease and illness. However, these factors have not been well studied in individuals who are relatively well adjusted after SCI. This study aimed to describe personality, cognitive functioning, and social support among individuals who have been identified as flourishing after traumatic SCI.

Design: Cross-sectional

Setting: Community

Participants: Community-dwelling Veteran and civilian individuals with traumatic SCI who were identified as flourishing (based on a cut-off score of 41 on the Flourishing Scale; Diener et al., 2010) as part of a larger study of successful adjustment after SCI. A stratified sample of 60 individuals from the larger study was compiled, of which the responses of 52 were used in final analyses.

Methods:

Main Outcome Measures: Stroop Neuropsychological Screening Test (SNST); NEO-Five Factor Inventory-3 (NEO-FFI-3); Interpersonal Support Evaluation List-12 (ISEL-12); demographics; injury characteristics.

Procedures: With the participants’ consent, research staff orally administered the SNST and questionnaires during face-to-face in-person interviews.

Data analysis: Frequency analysis, parametric and nonparametric (when normality was violated) mean comparisons, and bivariate correlations were used for analyses.

Results: Most participants were male, white, unemployed, married, and had at least a high school diploma or GED. The largest proportion of the sample (33%) reported over \$80,000 annual income. More than half lived in rural areas and had thoracic level injuries. Half were military Veterans, of whom few were service connected for their SCI. Half of the Veterans had been in combat. Average age was 51.02 years ($SD=14.43$), mean time since injury was 15.74 years ($SD=11.80$) with an average of 2.42 ($SD=1.85$) secondary conditions. Of those employed, average weekly hours worked was 33.79

($SD=12.81$). Among most mean comparisons conducted among groups of demographics and injury characteristics, there was only one significant difference on SNST, NEO-FFI-3, or ISEL-12 scores. There was a significant difference between Veterans and non-Veterans ($t (50) = -2.80$, $p = .007$), with Veterans ($M = 49.92$, $SD = 8.21$) reporting less Extroversion than non-Veterans ($M = 57.57$, $SD = 11.01$). There were also few significant correlations among continuous variables examined. Among the primary variables of interest, there was a significant positive relationship between ISEL-12 and SNST Color-Word scores, positive relationship between conscientiousness and extraversion, negative relationship between conscientiousness and neuroticism, negative relationship between extraversion and neuroticism, and positive relationship between Flourishing and ISEL-12. Given the age distribution in our sample and the different norms for scoring SNST scores for younger and older adults, we split the sample and reanalyzed correlations by age group as specified for SNST norms (18-49 years old and 50+). There were fewer significant correlations among those in the 18-49 correlations than when the entire sample was analyzed together. Many of the correlations for the 50+ were maintained when analyzed with the older group alone. Additionally, in the 50+ group, there was a trend toward significance (though not a significant correlation) between ISEL-12 and SNST Color-Word ($r (36) = .39$, $p = .019$) as well as number of secondary conditions with openness ($r (36) = .43$, $p = .010$). These results suggest that these outcomes are more impactful for older adults who perceive themselves as flourishing compared to younger adults.

Conclusions: In this sample of well-adjusted individuals, results suggest that executive function, social support, higher extraversion, and lower neuroticism were related to flourishing more so for older adults than for younger adults with traumatic SCI. Further results suggest that military Veterans with traumatic SCI are less likely to be extroverted than civilians who have never served in the military. The importance of intact cognitive functioning has been identified in older adults in the general population, and may be particularly important to help older adults with traumatic SCI thrive after injury. As extroversion may be one factor that contributes to soliciting and appropriately utilizing social support, interventions to help overcome less extroversion may be particularly important in older Veterans with SCI to help improve adjustment. Strengths of this study included sampling strategy, and limitations include the small sample size, which may have limited the power to detect significance.

Characteristics of Adults who Flourish after Spinal Cord Injury

Manuscript in preparation

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Abstract

Objective: The objective of this study was to examine the factors associated with flourishing among adults with spinal cord injury (SCI).

Design: Data for this study were extracted from a larger, multi-site, multi-method project which examined factors associated with successful adjustment among adults with traumatic SCI. Phase 1 of the study consisted of a cross-sectional mail survey while Phase 2 consisted of individual interviews and data collection with a stratified sample of 60 adults with SCI who were identified as doing well or “flourishing” after SCI.

Setting: Community with potential participants identified through four organizations (including three healthcare systems and one disability organization).

Participants: Phase 1 participants yielded 472 valid surveys. Respondents were predominantly White males ranging in age from 19 to 93 (mean = 53.7 years; SD = 15.2 years). Almost half (47.6%) had served in the military. Phase 2 participants consisted of a stratified sample of 60 adults with SCI who were identified through Phase 1 as doing well or “flourishing” post SCI. Stratification was based on military background, time since injury, and resource level.

Main Outcome Measure(s): The primary outcome measure for this study was the Flourishing Scale (FS; Diener et al., 2010), which was collected during phase 1. Additional measures collected during phase 2 included a measure of interpersonal support (Interpersonal Support Evaluation List, ISEL-12; Cohen et al., 1985), a test of cognitive flexibility (Stroop Neuropsychological Screening Test; Trenerry et al., 1989), and a measure of personality characteristics (NEO Five Factor Inventory-3, NEO-FFI-3; McCrae et al., 2005).

Results: Data analyses conducted using phase 1 data found that higher scores on the Flourishing Scale were found among individuals who were employed, had higher household incomes, better general health and fewer secondary conditions; however, the income and employment become non-significant when social comparison is added to the model. Data from phase 2 suggests that adults with SCI who are identified as doing well (as defined by a score of 40 or higher on the FS) perceive themselves as having good social support, lower than average characteristics of Neuroticism and, for at least young participant, cognitive flexibility at at least the population norm.

Conclusion: Adults with SCI can and do flourish after SCI and the ability to do so appears related to health, income and comparisons to others. It appears as if social support, cognitive flexibility and certain personality traits may serve as protective factors which facilitate a perception of a meaningful life.

Appendix D: Response Categories and Levels of Happiness

From Duggan et al., 2016, Online Appendix

Category: Resilience (N=99)

Happy All or Most of the time

...Challenges with everyday life don't tend to stop me and I bounce back fine.
I bounced back through adaptive sports and my education/career. Without them I would be miserable. My recovery was about getting back to my "normal" before injury.
After my accident, I was able to bounce back to mostly a normal life.
Every challenge has a solution and unless you try those challenges you will never know what those challenges will bring.
Facing adversity and bouncing back is something I have done most of my life.
I am good at compensating. If I can't do something, I looked for a new way to do it.
I am very good at facing challenges.
Experiences prior to SCI were important after SCI.
I broke my back when I was eighteen I've learned to just push through the most difficult situations. I think it has made me a more resilient person.
I don't believe in the word "can't". It's either "I don't want to or I'll try."
I don't give up when I have a problem and I am persistent to overcome it.
I have been able to maintain my resilience when faced with challenges since my injury due to my personal growth in the past year and a half.
I just say 'I can, watch me prove you wrong.'
I'm rubber; you are glue whatever you say and bounces off(f) and comes back on me?
I'm very adaptable and have faced many abrupt changes in my life.
Purpose in life and sheer force of will can go a long way in overcoming major challenges -
One word that describes me, tenacious." I have also been called 'very intense.'
... it's a matter of trying and adjusting and trying some more.
I will bounce as high or as far as I am willing or able to go.
Never give up!

Adapt and overcome
My disability has made me very adept at dealing with adversity.
In high school, my senior year, I had to "bounce back" from a down junior year to get into a good college.
...I have never been fazed by the adversity I face and I take pleasure in defying the odds.
It is a constant battle, but after so many years you learn to bounce back quickly;
It is more difficult to "bounce back" emotionally, especially when trying to accomplish routine tasks that should take a minute or two but turn into 10-15 minutes or more.
Just 'keep on pushing' I find there are many more people worse off than myself.
just...never give up!
I always try to do things for myself before asking for help! I do get frustrated when I cannot do something but usually figure out a way to accomplish the task.
Mentally I am very strong and have been able to make the best out of bad situations through my entire life (prior and post SCI).
Most of my resilience is due to...my strong support system.
The chronic pain makes it hard to bounce back.
After my accident I received 1.5 months TX at a trauma hospital followed by 7 months at a comprehensive rehab facility. I think current, shorter rehabs result in discharge too soon not allowing decent level of adjustment and coping skills.
Think outside the box to accomplish activities etc. To stay independent.
I try to face every challenge. 90% I succeed.
I thrive on challenge, when I am told it can't be done is when I don't procrastinate and sometimes get something done. Being a residential builder and rough carpenter help build character, some would say I am hardcore.
I would rather do things myself and I will if I can, but I also will ask for help if I do need it.
The best ways I've found to bounce back is to help others and humor.
Distraction with activities- computer/family support
It is very hard when the govt restricts your monthly income so any set back is very devastating.

I seem to have good common sense have the ability to work things out I am good at rigging things up that work for me
I will try anything - I try even if I fail. Able to move on if things do not work out.
Strong will to live...
Very difficult but I try
Wish I were younger and better physically to "bounce back". Wish I didn't tire so easily.
Art with mouth
Finally, being back at work has helped me a lot.
Driving and working on cars, trucks, grass cutting, and active in VFW
Sometimes when things are in my favor like working on my project car...
I started feeding my horses/doing barn chores while still in a back brace. I was riding my horses <6 months after the accident and competing <1 year afterwards.
Apart from restructuring one's life after a SCI, one of the hardest readjustments has been, what to do with oneself, after retirement from work. The ability to work after my accident ... was in my opinion, a life saver. I'm still trying to figure this one out (retirement). Understanding the limited options one has from a wheelchair, wasn't that much of an issue, when working. I took an early retirement (pending layoffs) because the work I enjoyed was going away and the contraction of the printing trade offered few other positive options.
I spend a lot more time around the house doing domestic chores (cooking and laundry), listening to an eclectic variety of music, working in the garage on bicycle / hand cycles and I'm planning to start (single hive) beekeeping again this Spring.
Bouncing back? There is no returning to the major things I did: the practice of [my profession], running along rural country roads, large scale vegetable gardening and extensive care of the grounds around my home. And I miss these things very much. One would think I could still teach ...but even that is limited. The major teaching need is showing students what to do with patients ... (and this requires an ability of my trunk muscles to upright myself after leaning over - which I cannot do). Yes, occasionally, there are lectures I can give and articles I can get published, which gives some satisfaction, but it's not the extensive participation in [my profession] that I had before.
And, I do have a stand-up, stationary exerciser ... which provides an upper body workout of some intensity. I also have an arm operated tricycle that I can take out on the country roads, but getting on and off safely is a bit tricky, and is best used when my wife can 'spot me' while doing this (this has led to infrequent use of this). I also got my John Deere utility tractor modified so I can get up on it. But, again, help is needed to most safely get on/off of it- and in this case having a stronger/male person

spotting me on this procedure is best, so he can also help in doing 'grounds care' cleanup of tree/bush trimmings. This need for a hired person has limited my participation in this grounds/tractor use.

But these things do not adequately replace the previous things I did.

I do try to keep up with what's happening in the world, by reading newspapers, magazines and following broadcast radio/television news- and I follow several TV series shows.

When I graduated

Happy Some of the Time

"Pick ya self up, dust ya self off, and start all over again.

Bullheadedly independent

Biggest challenge of my life, haven't been able to complete, yet.

Bounce back is very hard and very challenging. You have your good days and your bad days.

Bouncing back becomes more difficult in old age.

I try to never give up! After all these years it's hard to keep it up.

...I feel that my ability to recover from current and future medical issues is diminished due to spinal cord injury and age.

Even though the deck is stacked against me I have to keep getting up and moving forward because other people still depend on me...

Felt like I was bouncing back when I had regular PT. Insurance is no longer paying.

Older I get, harder it is, longer it takes

'press on' all you can do

Perseverance is the word I would use to describe myself

Try to be a problem solver

Get up = fall down + I

I bounced back at first, but it has become harder to fight all the time.

I don't let many things get in my way when there is something to be done.

Its hard, but necessary in life

I don't take "no" for an answer.

...It's always been two steps forward and five steps back. In that time I have pieced together a lot of successes. I always try to dust myself off

...I tell myself I'm the only one who has control of my life and can make it or break it, only me. I pull myself up by my bootstraps and move on.

I used to be able bounce back from any situation before my accident. Now I can't because of my spinal cord injury.

I've always been the type of person that if you tell me I can't do it, then I will find a way to do it. I'm proud that I live by myself after my spinal cord injury.

Try to do can about situation and sometimes think if I can keep trying results will be better.

I prefer not to argue

Patience

Much harder to bounce back now than it was 10 years ago or more.

My family and I have used many illustrations to reflect my resilience: Tigger, "bounce and re-bounce" etc... I know how to bounce.

Perseverance is the word I would use to describe myself.

You have to be flexible and open-minded. I had to learn entirely new skills, but now I have a better, higher-paying job than I did before my SCI. Some said I went back to school/work too quickly, but that was the best choice for me, I didn't want to become a 'professional patient.' Realizing I could still make a living and support from my family really helped me improve my outlook on the future.

I say to myself- this time will pass- when things become too difficult.

It's not always easy to bounce back. The move from Michigan ... was a plus because of the weather. The VA is beginning to help me with [medical issues and supplies] but appointments are hard to arrange with VA help and doctors.

Even though I had a good recovery following my initial injury and more recently had a good recovery following rotator cuff surgery last year; I feel that my ability to recover from current and future medical issues is diminished to spinal cord injury and age.

I am growing tired

...I don't think anyone bounces back after an SCI. You just become determined to get back as much as you can.

I'm going to school full time studying for a degree in CADD. I also play in pool leagues and enjoy them.

I would have answered strongly agree to every answer if it was not for a forced change in position at work in the last 6 months.

For about 90 days I have been practicing yoga...I cannot express enough how it has helped me regain some of my flexibility, balance, and overall happiness.

Happy Infrequently or Never

I bounce back well because I have always had to. I don't quit.

I have ups and downs when it comes to bouncing back. Sometimes I feel like giving up and other times I feel I can do anything.

My ability to bounce back has been affected by time and attempts to deal with a medical system that caress less and less for my welfare.

It is getting more and more difficult!

I can't bounce back so fast.

I never give up.

I no longer face problems/challenges head on. Instead I hide hoping these things will blow over or just go away.

I quit.

There is no such things as "bouncing back" from a SCI that leaves you in chronic constant pain for 10 years +.

Category: General Outlook (N=82)

Happy All or Most of the Time

The past is behind you. Stop looking back and focus on the present (what you can do and accomplish) future goals.

Be happy with what you have NOT what you didn't do or can't do.

I draw a dark line between 'acceptance' and 'adjustment' when it comes to my disability. My somewhat flippant answer to the question of how long it took me to adjust: 'I plan on being done with it a week from Thursday.' I have never adjusted well, but have accepted my situation (positively) through somewhat fatalistic/naturalistic language like 'Luck of the Draw,' 'go with the flow,' 'it is what it is,' and 'shit happens.' Also, my sense of curiosity -- 'I wonder where this will take me' -- has always been a prime motivator, and usually provides the resiliency to get through a situation or set-back.

Generally, I believe you can do anything you put your mind to.

i believe that i have to live to the best of my ability. if i can't do this then do that. i don't want to waste time feeling sorry for myself, cause there's only so much time left. i'm very fortunate to have a supportive family. because of my attitude, my extensive life experiences and advanced education many people seek my advice and counsel. this is very rewarding to me. also as i lived my life i was heavily engaged in it. i've done so many things i wanted to do do my bucket list is very short.as a result i don't lament about what i can't do but celebrate what i've done.

...Positive attitude, must move up or you will go down.

I put a strong emphasis on my healing because of...things to look forward to, work to do, people to help.

Attitude- eat right. Set goals

You either "get busy living or get busy doing".

I am self-care (Veteran) I do it all, I have to but doing for myself gives me a sort of high. I feel good after clearing, cutting grass, etc. I could never live some place where everything is done for me.

Keep in mind that the harder you work at having a better life the better your life will be.

Life is precious. Everyone has challenges and while paraplegia is visible there are many with tougher issues. There is joy in overcoming challenges. Everyone can do it when it's easy.

...I try to take a realistic view of my options and try to choose the one that address the challenge and makes me happy. This particular philosophy has worked well for me before and after my SCI.

Attitude is key. Having a positive outlook on life helped me accept my abilities and their differences.

The restoring medicine in any temporary defeat is to face it. Zero in on the things I have instead of the things

...I have accepted my situation (positively) through somewhat fatalistic/naturalistic language...go with the flow....it is what it is...

I have a good attitude toward life and people who I know- I hardly ever complain- even though I am hurting I still don't complain. I enjoy most every aspect of my life to the fullest.

What I have learned from the situations that I have faced since being a T5 complete is follow the doctors instructions, and be completely upfront with them on all of your health conditions. And most of all pay attention to what your body is telling you. Because in the surgeries in which I have needed, the doctors always tell me that they appreciate me following their orders because it makes their jobs so much easier. Because I do care about my well-being.

Everyone has always told me I've had a positive attitude.

By focusing on others, it makes what happened to me seem less important.

Usually I try to be optimistic about my daily life with the help of my wife who takes care of me

Control only what you do control (yourself); influence what you can and the rest will settle.

Being able to address obstacles with a sense of humility, and having fun with the chair.

Drop back to remind myself what is most important. I think it's "being a good person". With that in mind, I think of what to do next with the challenge.

Each day is a blessing--the good, bad and challenging we may face. Tomorrow is new day, a new page of life.

...my parents raised me and instilled that I can do anything.

Life goes on whether you win or lose. Learn to accept change and life is a lot better to deal with.

I never cared much what people thought of me before the injury; I think this helped a lot after.

I always try to have a positive outlook. I try to fix things so as to have a positive outcome. I have faith in God. Love my life, sunshine, and green grass. I love my wife and family.

I approach life and problems associated with it one day at a time

Positive attitude goes a long ways.

I view the glass as being half full

I feel that you accept what life deals you...Learn to control future problems to the best of my ability.

I have a good attitude toward life...
One day at a time, eat right and sleep right
I have a positive outlook about life.
Positive attitude – [you] must move up or you will go down.
I like working on problems that make me think on how to get it working or be resolved. I also accept to the point when the problem is one that I or anyone else can't fixed.
If you don't do it, nobody else will.
Do what you enjoy.
While setbacks or problems related to my condition can be very frustrating, especially things like equipment breakdowns, I try not to get emotionally invested or bother by day-to-day hassles not related to my condition.
Always ask yourself: If not you, then who?
I look for the good in all things
Just continue to be yourself and keep working hard to get back on your feet.
...go backwards or forward. I'm not going backwards. Have to stay positive...
Live my life by two mantras: (1) It's not about where you been, but where you're going. (2) From Victor Frankel, "Man's Search for Meaning". "If you find mean(ing)/purpose in life, the "how will take care of itself ...teaching life lessons...my saving grace.
Purpose in life and sheer force of will can go a long way in overcoming major challenge.
It's up to me, go backwards or forward. I'm not going backwards, have to stay positive, but it is hard. But I'm alive and my 3 girls need me. I have a whole bucket of problems, so I just put a lid on it.
I just try to do the best I can. The quadriplegic thing wasn't my choice but I'm trying to make the best of it.
I believe I gained a better attitude about my disability from a few experiences during recovery. The moon info sessions during in-patient rehab were valuable. A positive therapy helped my attitude. I was in outpatient therapy for a few months, then at [another facility].
There is a solution to every problem. I am happy to be alive each day and share my smile or laugh with others. I am in gratitude.
...and I take one day at a time.

Positive outlook. Support[ive] family
What hinders us only makes us stronger.
Life= fall down + I
Just do the best that I can with what my ability is.
Work smarter, not harder. If you can't really use your body, use your mind.
Keeping a positive attitude and religion, you can't change the past, only the future
I think I've done great and though I don't have everything I need, I still am fortunate and live a very active life.
I am very analytical and don't let emotion drive my direction. I try to limit variables that may contribute to issues that arise. I only typically measure and change one variable at a time so I can see or understand the variables impact on my life.
Yes, when a person hits rock bottom in life; there is only one way to go. Never feel sorry for yourself, because all you have to do is open your eyes and note there are many people more deserving than yourself!
There is no returning to the major things I did...And I miss these things very much...But these things do not adequately replace the previous things I did.
Happy Some of the Time
Get up= fall down+ I
Even though the deck is stacked against me I have to keep getting up and moving forward because other people still depend on me. Too bad jobs are not available for the handicapped. It would be nice to earn a living and support my family.
I always try to look on the bright side...
I am a positive person. ... but my injury have held me back...and that holds me back not only financially but emotionally.
I believe this trip is our only go-around in life...I've been tortured almost every day since my accident. I learned to turn pain into a positive. I live each day as full as I can...
Best I can in a wheelchair
I have my pity parties then I tell myself I'm the only one who has control of my life and can make it or break it, only me. I pull myself up by my bootstraps and move on. Everyone is caught up with their own lives and issues so with or without them I have to march on otherwise what's the point!

Bullheadedly independent

Be a kid, think how I'm going to get it done

...after my injury I have really felt as though my life has stopped.

I have been known for my ability to see the good in any situation. 'You always have a smile on your face' is not an uncommon statement to hear from others. However, this experience has been the most taxing to date in my life. I sometimes feel I have 'met my match' as it were or even 'got the challenge I asked for'. So far I seem to be managing, but just barely.

I have done well in the past...I'm not at a high point...but I'll keep swinging...

I don't like to sit around worrying, I look for ways or ideas to try to make myself feel better. I like to walk and exercise when I'm able to. I try not to dwell on negative things. I try to talk to people with the same symptoms I have to get some ideas on what I can do to make things better.

I try hard to remain optimistic in the face of a challenge.

Happy Infrequently or Never

I look at every day as an opportunity to be the best person I can for myself and, more importantly for the people around me.

I have worked through many issues over time. Sometimes it takes a lot both physical and mentally but I have managed. And I still have moments of 'why me' attitude.

When I broke my back and had surgery, I tried to be optimistic, but over the years of chronic pain, I have been worn down...

Confident life is better than death.

The drugs used to treat my SCI have completely ruined my life.

When you are asset everybody know you, when you become a liability nobody knows you. The longer you are a liability the worse it gets. Look at Michigan no-fault insurance. They trying to get off the hook and with all our money we paid into.

Category: Social Support and Social Relationships (N=49)

Happy All or Most of the Time
....I'm very fortunate to have a supportive family.
I put a strong emphasis on my healing because of my family...
...I do have many friends who help me as I live alone.
...Good support from friends that won't keep the chair from letting you do things.
...family.
...I am also blessed by a wonderful wife and family. I also appreciate my medical care and doctors.
Having a good wife and family is all important.
...I love my wife and family.
... I also benefited from being around other active disabled while biking, playing basketball, and various other activities.
I fear some sort of physical challenge in old age will make it too difficult for my family to deal with.
I have a lot of support from my family and friends...
Support[ive] family
... I have two children that have kept me motivated to not give up and live life as independently as possible.
...also, my family and support system is incredibly important to my ability to "bounce back".
I have my down days but thank God I am alive and have so many people that support me in anything I do.
In the 17 years since my accident I have never dealt with bouts of depression or anger because of my...family and friends.
...But I'm alive and my 3 girls need me.
Strong will to live because I am a very happy married man with a loving wife.
..My children and teaching life lessons are my saving grace.
Most of my resilience is due to...my strong support system.

...My husband was a rock, and the care I got through [the health system] was great.

My...kids and friends.

...my husband; my family...

... And I spend fairly regular time with my wife, who watches over and tries to maintain my mental status.

My spouse is very supportive as are my children...

Stay engaged and help others. In the long run it's about service to others....

...I am a very happy married man with a loving wife.

Usually I try to be optimistic about my daily life with the help of my wife who takes care of me

The 1st two years were pretty rough but after that I was introduced to wheelchair sports from a group of my peers. It was my time to make a choice...

The single most important factor in being happy, productive, healthy is the support of family and friends...

Only when I encounter people who are not disabled, I do have a problem setting them to engage on a more personal level. Is it ignorance?

My family and friends keep me 'up.'

I was wounded in Vietnam a very troubled time in our country and own lives, what helped me most after being wounded I was sent to [an Army Hospital]. It was the doctors, nurses, and the people there that helped me most. They helped me come back home because in general the American peoples at home in America hold us Vietnam Veterans, won what did we do to them!

The support from family and friends to encourage.

When you think about family and how this challenge will help you and the around you, you overcome.

Happy Some of the Time

...I have to keep getting up and moving forward because other people still depend on me.

Good family and friends support are a huge help.

Having supportive family/friends, not having to do it alone, having someone there to encourage you to keep going...

Need help with social skills again

My wife takes really good care of me

...I try to talk to people with the same symptoms I have to get some ideas of what I can do to make things better.

Some days I feel more optimistic than others. I wouldn't say I'm a depressed person, but I can definitely get down on myself. I feel like my disability has made me not as social. I feel like I wish I could have what my friends have: a boyfriend/husband, kids and house, and just a happy little family. I'm successful on the academic and career front, but not the social front.

When I got hurt my wife was 7 1/2 months pregnant, then a year after my accident our house burnt to the ground, 9 years later my wife had an affair and subsequent divorce. I had a wonderful life and marriage (I thought) till then. The divorce by far has been the roughest thing to overcome and if it were not for my 2 daughters I would be in a bad place. I think I live my life by example for my girls

My wife's support helps. The love of my family helps.

I always try to look on the bright side, but if I can't, I have my family to support me.

The support my family and friends, would have no "drive to live and little future. They make me strive to be better and to go on a little further along life with a sure step.

Happy Infrequently or Never

...I look at every day as another opportunity to be the best person I can for myself and, more importantly, for the people around me.

Support and care from family.

Would like to help others, sick, elderly, etc. but unable

Category: Religion and Spirituality (N=36)

Happy All or Most of the Time

I put a strong emphasis on my healing because of my family and faith, things to look forward to, work to do, people to help.

Meditation and self-healing with Reiki.

A believer in a higher power.

Every day is a blessing...

God give me the "strength"

Only by the grace of God go I.

God helps me through prayer by His people and by myself. He guides me by His word also (i.e. the bible).

...I have faith in God.

I believe in a God that knows my trial and helps me through each step. I believe that if I depend on his strength that I can succeed no matter what level of function I have or don't have.

I believe my faith or Jesus Christ as my savior and His leading in my life gives me the strength to live my life.

My faith is my number one. I am truly blessed with support and God.

I have my down days but thank God I am alive and have so many people that support me in anything I do.

It all comes [down to] God. Always keep your faith.

... I get up each day, try to remember to thank God for all my blessing.

Most of my resilience is due to my faith...

My faith helped me tremendously

My faith in God, our Creator, helps me through my challenging moments.

My faith in God really blossomed with my SCI. I know I am right where He wants me to be. If my life were to be different He is the only one that could change it. He has also blessed me with a great sense of humor. Believe me with this lifestyle there really is humor. Hey, it's better than crying!

Self-worth is not from my abilities, my friends, or lack thereof - I am crucified with Christ therefore I will live. Everything in this life will eventually fade for everyone - so cling to what is eternal and everything seems to fall into place.

....I count my blessings daily...

The Lord Jesus Christ is my strength, and in Him I put my trust.

The promises for our future that are in the Bible help me to be positive and excited for my future.
(Psalm 37:29; Revelation 21:4)

Keeping a positive attitude and religion, you can't change the past, only the future

In the 17 years since my accident I have never dealt with bouts of depression or anger because of my faith, family and friends. I have never been fazed by the adversity I face and I take pleasure in defying the odds.

My faith

'Religion'

Stay engaged and help others. In the long run its about service to others and we must put God back into our principles. Without a moral compass we have no direction then anything goes and that's wrong.

Each day is a blessing- the good, bad and challenging we may face. Tomorrow is a new day; new page of life.

I was paralyzed from the neck down for 2.5 months. After I got up out of my wheelchair, I never wanted to sit in a wheelchair again! To this day I still refuse to sit in one! I credit my family, and my faith in god to all my recovery. I was 19 when I was injured. Fresh out of the Marine Corps. Marines never give up. I never did, nor will I ever. God is awesome!

Happy Some of the Time

Amazing Grace.

Attempting to get through this ordeal with God's Grace.

You have your good days and your bad days but above all blessed to be where I am by God grace and mercy

I sometimes believe it is a test from a higher power (or punishment for wrongful acts.)

I am a born-again Christian. Even after death, I have hope.

In spite of my physical predicament I do have many blessings to count and I often count them to keep things in perspective. Also, the older I get the less time I have to be here in this world. Each day I live is one less day I have to serve in this prison sentence that is paralysis.

Faith and trust in God

Category: Physical (N=28)

Happy All or Most of the Time

Have faced about 3.5 years of fighting severe pressure ulcers and have been subject to a lot of bed rest.

Have medical challenges unrelated to SCI which impacts quality of life.

What I have learned from the situations that I have faced since being a t5 complete is follow the doctors' instructions, and be completely upfront with them on all of your health conditions. And most of all pay attention to what your body is telling you. Because in the surgeries in which I have needed, the doctors always tell me that they appreciate me following their orders because it makes their jobs so much easier. Because I do care about my well-being.

In the last 10 years I had a heart attack; 6 weeks later broke my neck. My daughter was diagnosed with leukemia. U of M saved her life, and lost my mom two months ago. But I get up each day, try to remember to thank God for all my blessings!

I have balance issues, given time I can pick myself up.

Sometimes when things are in my favor like working on my project car, it's difficult getting up and down more than ever before. And bending for something you drop or can't pick up.

VA need to send my medications on time! I go several and a couple of times over 2 wk without getting them. It causes me to spasm uncontrollably. 3 times out of bed and out of my wheelchair when getting in and out! Causes bad withdrawals too. Your going to kill people this way! Or get a lawsuit!

The chronic pain makes it hard to bounce back. The pain drugs have had terrible side effects and have not worked.

When I fell in Florida, I was paralyzed. When they opened up my neck, my spine started pulsing...

Happy Some of the Time

....my largest challenge is my stamina. I have not been able to increase it by any substantial amount.

...I've been tortured almost every day since my accident. I learned to turn pain into positive.

...It's hard to live with chronic pain; it takes a toll on me physically and mentally.

Just chronic debilitating pain

For about 90 days I have been practicing yoga...I cannot express enough how it has helped me regain some of my flexibility, balance, and overall happiness.

When I broke my neck, I was told I wouldn't walk again for 6 months to two years and I am able to walk after 6 months.

When it comes to my health I am very in charge of it. As soon as I have a problem I get it checked out.

I have had 12 separate surgeries in 15 years. It's always been two steps forward and five steps back

I have persistent pain at the level of my injury (T4). If I could manage that my outlook would be better.

Since my fall 3.5 years ago, most all feelings have come back and just wish I could get help to gain strength back, and lose weight I have gained but need help so I can walk again. I am sure someone could help with therapy.

Life has not been easy for me since after the accident. It has been pains all over my body and three surgeries on the two shoulders and neck. I really need employment to assist in family expenses and my personal pocket money too.

...since my neck incident I have been discovered to have liver cancer.

Happy Infrequently or Never

When I broke my back and had surgery, I tried to be optimistic, but over the years of chronic pain, I have been worn down...

Nerve pain drives me crazy 70% of the time.

Due to a severe ulcer that I am going to Ann Arbor VA this month for surgery that was caused by a bad shower chair that took 1 year to replace I hope to become more active and get a life again. Right now I spend 20 hrs a day in bed.

I still would like to walk again so that would be a challenge that I would be looking forward to.

I have tried to be optimistic but over the years of chronic pain I have been worn down.

...the antidepressant used to control my nerve pain has caused severe depression... that I cannot escape from

There is "no such thing" as "bouncing back" from a SCI that leaves you in chronic constant pain for 10 years.

Category: Mood (N=19)

Happy All or Most of the Time

I cried every day for a few months....

I am happy to be alive each day and...

At this point, I'm happy for the experiences and memories but ready to wrap things up - not suicide, just content for what has been-

...I do get frustrated when I can't do something but...

I fear some sort of physical challenge in old age will make it too difficult for my family to deal with.

I experienced PTS disorder. It comes and goes. Have difficulty in moving forward- no motivation- no drive. Fear and anxiety. Drs. don't necessarily care to treat me for this. They expect me to just get over it!

In the 17 years since my accident I have never dealt with bouts of depression or anger...I take pleasure in defying the odds...

Happy Some of the Time

Every time I've found myself at my lowest point, feeling like I can no longer deal with paralysis, I always manage to see someone much worse off than I am. In spite of my physical predicament I do have many blessings to count and I often count them to keep things in perspective. Also, the older I get the less time I have to be here in this world. Each day I live is one less day I have to serve in this prison sentence that is paralysis.

...practicing yoga...I cannot express enough how it has helped me regain....overall happiness.

I get frustrated when I can't do things I used to do before my spinal cord injury. My moods are up and down constantly.

Some days I feel more optimistic than others. I wouldn't say I'm a depressed person, but I can definitely get down on myself. I feel like my disability has made me not as social. I feel like I wish I could have what my friends have: a boyfriend/husband, kids and house, and just a happy little family. I'm successful on the academic and career front, but not the social front.

...I'm not at a high point, but...

... . I've recently quit smoking because I am not happy with how little I can contribute to the world around me however I'm not finished living and there's so much I still want to do in life I just feel stuck :(

I have my pity parties...

Happy Infrequently or Never

My ability to bounce back has been affected by time and attempts to deal with a medical system that cares less and less for my welfare. I am in desperate search for a doctor supportive of assisted death. I've considered starting a crowd sourcing project for the purpose, and have no doubt it would be funded overnight- in the same world where I can't get a ride to the doctor or grocery store.

The drugs used to treat my SCI have completely ruined my life. The anti-depressant used to control my nerve pain has caused severe depression that I never had before and I cannot escape from.

I can't seem to overcome the frustration of not being able to do what I once could, anger is an issue. What I most liked to do I can't do any longer. I should be happy with what I have but I'm not.

Too depressed

Look at Michigan no-fault insurance. They trying to get off the hook and with all our money we paid into. They have plenty of money, but will not open the MCCA books. By the time they have to, the books will be fake

Category: Comparisons (N=18)

Happy All or Most of the Time

...someone else always has it worse than you.

I think I 'bounced back' faster than most after my injury. I cried every day for a few months, then I met at 'quad' who was physically much worse off than me, but living his life just fine with a good job, still had fast cars, women attracted to him. It was at that point I realized there was no reason I could not do the same things and more.

Everyone has problems, many are worse than me...

I find there are many more people worse off than myself.

I always take into consideration that there are always people worse off than me.

I know there are people worse off than I. So whenever I want to complain about things I want to do and can't I try to remember that.

I realize that there is someone always worse off than me.

More people than myself (are) worse physically than me.

The 1st two years were pretty rough but after that I was introduced to wheelchair sports from a group of my peers. Once I saw how they were dealing with SCI etc... it was my time to make a choice. Sleep, drink, and drug my life away. -Or- move on life and be thankful for/with what I have. I count my blessings daily :)

When I fell in Fla. I was paralyzed, when they opened up my neck, my spine started pulsing. I could have been paralyzed for life. Things can always be worse.

Realizing that it's not the end of the world and could always be worse.

Every time I've found myself at my lowest point, feeling like I can no longer deal with paralysis, I always manage to see someone much worse off than I am. In spite of my physical predicament I do have many blessings to count and I often count them to keep things in perspective. Also, the older I get the less time I have to be here in this world. Each day I live is one less day I have to serve in this prison sentence that is paralysis.

Happy Some of the time

I feel like I wish I could have what my friends have: a boyfriend/husband, kids and house, and just a happy little family. I'm successful on the academic and career front, but not the social front.

You learn to accept your condition knowing that it could be worse.

Knowing things could always be worse.

We all have a cross to bear, others have it better, many, have it much worse.

I know things could be worse. My main problem is having enough money to take care of my wife and monthly bills every month since they have cut my check down so low. It is hard for us.

You learn to accept your new condition, knowing it could be worse.

Category: Resources (N=10)

Happy All or most of the time

It is very hard when the govt restricts your monthly income so any set back is very devastating.

I would like my vehicle fixed. I need \$150 for a new electric fuel pump. Another \$80 for used tires. Has lift and driving controls. I feel trapped at home.

Happy Some of the time

I know things could be worse. My main problem is having enough money to take care of my wife and monthly bills every month since they have cut my check down so low. It is hard for us.

Felt like I was bouncing back when I had regular PT. Insurance is no longer paying.

Even though the deck is stacked against me I have to keep getting up and moving forward because other people still depend on me. Too bad jobs are not available for the handicapped. It would be nice to earn a living and support my family.

Since my fall 3.5 years ago, most all feelings have come back and just wish I could get help to gain strength back, and lose weight I have gained but need help so I can walk again. I am sure someone could help with therapy.

Life has not been easy for me since after the accident. It has been pains all over my body and three surgeries on the two shoulders and neck. I really need employment to assist in family expenses and my personal pocket money too.

If insurance would have covered more therapy, I think I would have walked again.

Happy Infrequently or never

Lack of transportation, employment

... I've considered starting a crowd sourcing project for the purpose, and have no doubt it would be funded overnight- in the same world where I can't get a ride to the doctor or grocery store.

Appendix E: Participant Feedback Responses

Participant Feedback Responses

Background of Participants

Please select each word below that applies to you as a lesson learned while growing up or a lesson from your military service.

	Count (n)	Frequency (n/18)
Work ethic	18	100%
Responsibility	17	94%
Ability to adapt	16	89%
Accountability	16	89%
Respect	15	83%
Discipline	14	78%
Independence	14	78%
Integrity	13	72%
Attitudes	11	61%
Listening	11	61%
Patience	11	61%
Perseverance	11	61%
Cooperation	10	56%
Improvise	10	56%
Relationships (and their importance)	10	56%
Communication	9	50%
Confidence	9	50%
Organization	9	50%
Survival	9	50%
Goal-setting	8	44%
Leadership	8	44%

Feelings and Thoughts Immediately after SCI

Please select the feelings or thoughts you experienced immediately after your injury.

	Count (n)	Frequency (n/17)
Confident that I will figure it out	12	71%
Determined / determination	11	65%
Uncertainty - "I didn't know what to expect"	11	65%
Focused on recovery / walking	10	59%
Positive	10	59%
Worry / anxiety	9	53%
Anger	8	47%

Depression / sadness	7	41%
Acceptance	6	35%
Caught up in what I cannot do	6	35%
Feeling bad / feeling sorry for family members / feeling like a burden	5	29%
Helplessness	4	24%
Stunned	4	24%
Worried about others	4	24%
Discouragement	3	18%
Unsure / unfocused	2	12%
Broken / broken down	1	6%
Negative	1	6%
Suicidal	1	6%
Unphased by the injury	1	6%
Detached	0	0%

Path to Current Life and Sense of Flourishing

Please select the path below that is most similar to your experience.

	Count (n)	Frequency (n/17)
A process of hard work and determination	13	76%
Gradual process	7	41%
A series of choices	5	29%
Steady / no real changes	3	18%

Please select any of the turning points listed below that were important in your experience.

	Count (n)	Frequency (n/16)
Recognition of my ability and strengths	11	69%
Spirituality	9	56%
Independence / moving out on my own	8	50%
Wanting to make a difference for others / impact	8	50%
Motivated by others / importance of family and friends	7	44%
Changes in perspectives and approaches	6	38%
Motivated by opportunities	5	31%
Desire to prove others wrong	5	31%
Employment	4	25%
Increased social comfort	4	25%
Sports	3	19%

Please select any factor(s) in the list below that you associate with your adjustment process after your SCI.

	Count (n)	Frequency (n/16)
Need to move forward and get things done	13	81%
Learning what was possible	12	75%
Taking responsibility	9	56%
Find a sense of purpose and meaning	8	50%
Avoid negative thoughts	8	50%
Need to learn patience	8	50%
Finding a sense of acceptance	6	38%
Reconnect with who you are and pre-injury identity	5	31%
Allow yourself to grieve	3	19%
Disconnecting from people who don't understand	2	13%

High Points

Do any of these high points reflect your experience?

	Count (n)	Frequency (n/14)
Yes	14	100%
No	0	0%

Low Points

Do any of these low points reflect your experience?

	Count (n)	Frequency (n/16)
Yes	11	69%
No	5	31%

Current Thoughts about Life / Attitude / Outlook

Please select any of the thoughts or attitudes in this list that apply to you today.

	Count (n)	Frequency (n/17)
Feel thankful, lucky, and grateful	14	82%
Positive / good / life is good	14	82%
If you want something, work for it and earn it	13	76%
Everyone has their struggles	12	71%
Don't take anything for granted	11	65%
Optimistic, hopeful	11	65%
Experience regrets but not letting them consume me	10	59%

Happy / enjoy life	9	53%
Desire for a family and a good life - do what you need to do to get there	7	41%
SCI as a speed bump	7	41%
Life is not fair but you deal with it	7	41%
Life is life	6	35%
Taking it as it goes	6	35%
Realistic / day by day	5	29%
Things are the same - may take a little longer	5	29%
Pessimistic / cynical	0	0%

Behaviors Associated with Successful Adjustment to SCI

Working to Maintain Physical Health

	Count (n)	Frequency (n/17)
Bowel and bladder management	16	94%
Skin care - monitoring and prevention	14	82%
Exercise	13	76%
Weight management	13	76%
Develop a routine or structure	13	76%
Diet	11	65%
Medication management	10	59%
Listening to medical advice	10	59%
Being proactive	10	59%
Range of motion	10	59%
Pain management	9	53%
Blood pressure management	9	53%
Fatigue management	6	35%

Working to Maintain Emotional Health

	Count (n)	Frequency (n/17)
Focus on the positive / avoid the negative	13	76%
Problem-solving / figuring out what can be adapted and do it	12	71%
Return to work / school	11	65%
Keep your brain working	11	65%
Prayer	10	59%
Relationships / social networks	10	59%
Setting goals	10	59%
Be aware of / in touch with your feelings	8	47%
Learning how (and who) to ask for help	7	41%
Adaptive sports	5	29%
Meditate	5	29%

Talk to / work with a mental health professional	4	24%
Support groups	3	18%

Changing the Environment

	Count (n)	Frequency (n/17)
Adapting house, car	17	100%
Do-it-yourself projects	9	53%
Creating tools	5	29%

Things that Contribute to Feelings of Happiness

People

	Count (n)	Frequency (n/17)
Family, particularly children, including adult children and grandchildren	12	71%
Networks of friends	10	59%
Siblings who are willing to help	9	53%
A good support system	8	47%
People in general	6	35%
Others with SCI	5	29%

Activities

	Count (n)	Frequency (n/17)
Work you enjoy / employment / being productive	14	82%
Doing what you enjoy	14	82%
Keeping busy	12	71%
Volunteering / helping others	9	53%
Being able to get up and around and do most things that need to be done	7	41%
Return to pre-injury activities such as hunting and fishing	7	41%
Wheelchair sports	3	18%

Other Personal Factors

	Count (n)	Frequency (n/17)
Family foundation / how I was raised / parents	14	82%
Spirituality / faith / religion	12	71%
Good disposition / personality	12	71%
Financial resources	11	65%
Pets	6	35%
"My land"	5	29%

Approach to Life / Attitude

	Count (n)	Frequency (n/17)
Not dwelling on paralysis / accepting impairment and moving on	16	94%
Quest to be as independent as possible	14	82%
Determination / persistence	14	82%
You are responsible for your own happiness	14	82%
Taking on challenges and being able to overcome / pushing yourself	13	76%
Accomplishing things / getting things done	13	76%
Sense of purpose	13	76%
Recognize the impact you can have on your own life and its outcome, even with SCI	12	71%
Positive attitude	12	71%
Having goals and something to work toward	8	47%
The drive to prove people wrong, to work, to contribute	7	41%

Things that Detract from Your Feelings of Satisfaction or Happiness

Internal factors associated with health and impairment

	Count (n)	Frequency (n/17)
Pain	11	65%
Limitations on mobility	8	47%
Relatively minor nuisances and frustrations associated with physical impairment	7	41%
Increasing functional limitations - things are getting harder	6	35%
Self-image	6	35%
Neurogenic bowel and bladder	6	35%
Poor health	4	24%
Nuisance of needing to carry around supplies	3	18%
Frustration with the lack of independence / dependence on everyone	3	18%
Erectile dysfunction	2	12%
Negative thoughts and tendencies	2	12%

Interpersonal Factors

	Count (n)	Frequency (n/13)
Inconsiderate or negative people	7	54%
Concerns about children	5	38%
Divorce	3	23%
Lack of partner / relationship	4	31%
Suffering of others	4	31%
Perceptions of the public / media	3	23%

Environmental factors, including policies and physical accessibility

	Count (n)	Frequency (n/14)
Lack of accessibility	9	64%
Transportation problems	6	43%
Lack of money	5	36%
Insurance companies	4	29%

Recommendations for Those with New Injuries

Interactions with healthcare providers

	Count (n)	Frequency (n/16)
Stay informed about your own health and the things that are available to you.	10	63%
Have hope.	9	56%
Get your seating proper, get the lightest chair you possibly can, and adventure as much as possible.	7	44%
Listen to the doctors.	7	44%
Experiment. Do things differently.	5	31%
Advocate is a number one thing.	4	25%

Actions to take

	Count (n)	Frequency (n/17)
Don't give up on yourself.	11	65%
Keep your body healthy.	11	65%
Work to be as independent as you can.	10	59%
Build networks / make connections with people	8	47%
Stay active.	8	47%
Find ways to connect with people.	7	41%
Connect with peers with SCI / disability.	6	35%
Get involved / take advantage of services and organizations, like PVA	6	35%
Allow yourself to grieve but don't stop living.	5	29%

Things to understand or realize

	Count (n)	Frequency (n/17)
Realize that there's life after this.	14	82%
Get the most out of life that you can with what you can do.	10	59%
There are a lot of people out there that will help you that you aren't even aware of. Don't be afraid to ask for help.	9	53%
Don't let people tell you that the harder you work the better you're going to be.		
Sometimes the injury level you're at, that's all you're going to get back as far as your physical abilities, no matter how hard you work.	4	24%

Perspectives to adopt / suggested approaches to life

	Count (n)	Frequency (n/17)
Accept responsibility for your own life / health / happiness.	12	71%
Stay positive.	12	71%
Don't let your disability define you.	11	65%
Focus on what you can do, rather than what you can't do.	11	65%
Be proactive - "push, push, push."	7	41%
Be willing to tailor and adapt things.	6	35%
One day at a time.	5	29%

Critical Resources, Programs, and Policies

Information

	Count (n)	Frequency (n/16)
About your injury	7	44%
About what happens next	5	31%
About social services, benefits, attendants, insurance, federal programs, etc.	4	25%
Given during inpatient but also available later on	1	6%

Programs and policies

	Count (n)	Frequency (n/15)
ADA / accessibility enforcement	5	33%
Inpatient rehabilitation and continued outpatient therapy	4	27%
Employment / work supports	3	20%
Peer mentoring	2	13%
Personal care attendants	2	13%
Programs that support self-determination	2	13%
Programs to support independent living and participation	2	13%
Psychological and vocational counseling	1	7%
Support for PT / OT / recreation therapy	1	7%
Rules about durable medical equipment and supplies	0	0%